A STUDY ON KNOWLEDGE ASSESSMENT AND QUALITY OF LIFE IN INFLAMMATORY BOWEL DISEASE PATIENT

A Dissertation Submitted to
The Tamil Nadu Dr. M.G.R. Medical university,
Chennai-600032
In partial fulfilment for the requirement for the award of the Degree of

MASTEROF PHARMACY

in

PHARMACY PRACTICE

OCTOBER 2018

DEPARTMENT OF PHARMACY PRACTICE
KMCH COLLEGE OF PHARMACY
KOVAI ESTATE, KALAPATTI ROAD,
COIMBATORE - 641 048.

A STUDY ON KNOWLEDGE ASSESSMENT AND QUALITY OF LIFE IN INFLAMMATORY BOWEL DISEASE PATIENT

A Dissertation Submitted to
The Tamil Nadu Dr. M.G.R. Medical university,
Chennai-600032
In partial fulfilment for the requirement for the award of the Degree of

MASTER OF PHARMACY
in
PHARMACY PRACTICE
OCTOBER 2018

Submitted by
Reg No. 261640603

Under the Guidance of
Mrs. G. SATHYAPRABHA M.Pharm.
Assistant. Professor, Department of Pharmacy Practice.

DEPARTMENT OF PHARMACY PRACTICE
KMCH COLLEGE OF PHARMACY
KOVAI ESTATE, KALAPATTI ROAD,
COIMBATORE - 641 048.

Certificates

Prof.Dr. A.RAJASEKARAN, M.Pharm., Ph.D.,

Principal,

KMCH College of Pharmacy,

Kovai Estate, Kalappatti Road,

Coimbatore- 641 048 (TN)

CERTIFICATE

This is to certify that the research work entitled**"A STUDY ON KNOWLEDGE ASSESSMENT AND QUALITY OF LIFE IN INFLAMMATORY BOWEL DISEASE PATIENT"**submitted by **Reg No. 261640603,**isabonafide work carried out by the candidate at Gastroenterology Department, Kovai Medical Center and Hospital, Coimbatore, under the guidance of**Mrs. G. Sathyaprabha, M Pharm**Assistant. Professor,Department of Pharmacy Practice**.** and submitted to the Tamil Nadu Dr. M.G.R. MedicalUniversity, Chennai, in partial fulfilment for the Degree of **MASTER OF PHARMACY** during the academic year 2017-2018.

Date:

Place:Coimbatore

Signature

Prof.Dr.A.RAJASEKARAN,M.Pharm., Ph.D.,

PRINCIPAL

Mrs. G. SATHYAPRABHA,

Assistant. Professor, Department of Pharmacy Practice,

KMCH College of Pharmacy

Coimbatore-641 048

Tamil Nadu

CERTIFICATE

This is to certify that the dissertation work entitled **"ASTUDY ON KNOWLEDGE ASSESSMENT AND QUALITY OF LIFE IN INFLAMMATORY BOWEL DISEASE PATIENT"** is a bonafide work carried out by **Reg No. 261640603,** under my direct supervision and guidance at KMCH,Department of Pharmacy Practice, Coimbatore and submitted to The Tamil Nadu Dr. M.G.R. Medical University, Chennai, in partial fulfilment for the Degree of **MASTER OF PHARMACY** during the academic year 2017-2018.

DATE: **Signature**

PLACE: Coimbatore **Mrs. G. SATHYAPRABHA**

Declaration

DECLARATION CERTIFICATE

I do hereby declare that the dissertation workentititled**"ASTUDY ON KNOWLEDGE ASSESSMENT AND QUALITY OF LIFE IN INFLAMMATORY BOWEL DISEASE PATIENT"**was carried out at Gastroenterology Department, Kovai Medical Center and Hospital, Coimbatoreand submitted to The Tamil Nadu Dr. M.G.R. Medical University, Chennai, in partial fulfilment for the Degree of **MASTER OF PHARMACY,**was done under direct supervision and guidance of **Mrs. G. Sathyaprabha,**during the academic year 2017-2018.

Reg.No: 261640603

EVALUATION CERTIFICATE

This is to certify that the dissertation work entitledsubmitted by**Reg. No: 261640603,** to The Tamil Nadu Dr. M.G.R. Medical University, Chennai, in partial fulfilment for the Degree of**MASTER OF PHARMACY** in **PHARMACY PRACTICE**is a bonafide work carried out by the candidate at the Department of Pharmacy Practice, KMCH College of Pharmacy, Coimbatore, Tamil Nadu and was evaluated by us during the university examination held on October 2018.

Examination Centre: K.M.C.H College of Pharmacy, Coimbatore

Date:

Internal Examiner: **External Examiner:**

Convener of Examination:

Acknowledgement

ACKNOWLEDGEMENT

First and foremost I would like to thank **the God Almighty** for giving me the strength, health and happiness to keep going through out my work.

I would like to take this opportunity to express my deepest sense of gratitude and respectful regard to my beloved guide**Mrs G. Sathyaprabha, M. Pharm** Assistant .Professor, Department of Pharmacy Practice for her innovative ideas, moral support, sincere efforts and patience work. Because of her guidance only I successfully overcame the difficultiesthroughout the tenure of the dissertation work and I could able to improve myself.

I extend my special thanks to **Dr. S. Aravindh MD.,DM.,(Gastro) Department of Gastroenterology, Kovai Medical Centre And Hospital**, for his valuable suggestion, guidance towards my research work.

I express my heartfelt thanks to **Mrs. J. Vennila, M.Sc M.Phil. Statistics** for her expertness, assertivenessmotivation, valuable suggestions and support towards my study.

I am overwhelmed by the generous help, and enthusiastic encouragement offered by, **Dr. C. Sankar M Pharm, Ph.D,** Head of the Department**,Dr.CDhandapani ,M Pharm, Ph.D.**I express my sincere thanks and gratitude to my principal**, Dr.ARajashekaran**, M.Pharm., Ph.D KMCH College of Pharmacy for providing me with a cooperative and creative environment to enable me to work excellently.

I extend my sincere thanks to our beloved chairman **Dr. Nalla G. Palaniswamy** MD.,AB(USA)., and Madam Trustee **Dr. Thavamani D. Palaniswamy,** MD., of Kovai Medical CentEr Research and Educational Trust, Coimbatore for providing me with all the necessary facilities to carry out a work of this kind in a corporate hospital.

It’s my privilege to express my deep sense of gratitude andlove to my beloved dear friends Jithin Chacko, Priyanka E Kurian, Sangeetha K.N, Shahanas A and Elvy John for their support and help throughout the period. I take this opportunity to

acknowledge my dear juniors BasilBabu, Jiffintomy ,MukundParasuram, TeenaSiby, LoisaZeenaFeriah and Persis Pauline who helped me to collect the datas from time to time.

I am deeply in debted to my parents and brother for their invaluable affection, concern, encouragement and faith in me and for the prayers they have offered for me for the completion of this project work in a fruitful manner.

I take this opportunity to acknowledge my dear juniors for their memorable company.

Last but not the least, I thanks to all patients who were in my study for their kind cooperation for the counseling and I thank all the staffs in the Gastro Enterology Departmentwho helped me to collect the data.

ABBREVIATION

IBD	-	Inflammatory Bowel Disease
CD	-	Crohns Disease
UC	-	Ulcerative Colitis
CCKNOW	-	CrohnsAnd Colitis Knowledge Score
SIBDQ	-	Short Inflammatory Bowel Disease questionnaire
PSQ-18	-	Patient Satisfaction Form Quistionnaire
HRQoL	-	Health Related Quality Of Life
GIT	-	Gastro Intestinal Tract
NSAIDs	-	Non Steroidal Anti Inflammatory Drugs
IL	-	Inter leukin
TGF β	-	Transformig Growth Factor Beta
MADCAM 1	-	Mucosal Adhesion Vascular Addressin Cell Adhesion Molecule 1
LP	-	Lamina Propria
SCCAI	-	SimpleClinical Colitis Activity Index
SES-CD	-	Simple endoscopic Scale –Crohns disease
CRM ,CRI	-	Cumulative risk model,Cumulative risk Index
RFIPC	-	Rating Form of IBD Patient Concerns
HH	-	Hygienic Hypothesis

ABSTRACT

Inflammatory Bowel disease(IBD) is a generic term used to describe a group of chronic relapsing inflammatory disorders of the gastrointestinal tract, of which Crohn's disease (CD) and ulcerative colitis (UC) are the most common.Disease related knowledge plays a vital role in facilitating patient's acceptance of their diagnosis and compliance with active participation in the treatment of inflammatory bowel disease (IBD. The aim of this study was to identify the disease specific knowledge in IBD patients and to improve their health related quality of life. The knowledge assessment was done by CCKNOW and QoL was measured by SIBDQ. Among 74 patients, equal number of males and females were enrolled(37 each). Majority of the patients were in the age group of 20-40. The distribution of UC and CD in the study population was 36 (48.6%) were UC patients and 38(51.4%) were CD patients. relatives of 23 patients were having IBD. The mean CCKNOW score were found to be increased in the revisit period from baseline visit ($p<.001$). The mean score of female patients were found to be more than that of males. The association between different domain of SIBDQ with demographic charecters were analysed. It was observed that age and past history found that significant relation with bowel domain ($p<0.05$). The Patients were provided with the patient information leaflet and then the knowledge and Qol were shown considerable difference in the scores. The study suggests that patient education program is beneficial for the patients for improving their knowledge regarding the disease. There is no association between the knowledge and health related quality if life in IBD patients.

INTRODUCTION

Inflammatory bowel disease (IBD),is a chronic disease used to describe disorders that involve chronic inflammation of the digestive tract. There are two forms of IBD, Crohn's Disease(CD) and Ulcerative Colitis(UC), in which crohn's disease means the inflammation in the lining of the digestive tract, which often spreads deep into affected tissue. It is the transmural inflammation which affect any part of GIT from mouth to anus, most commonly in the end of small intestine may appear as patches. Ulcerative Colitis is the condition in which the entire colon is affected as a continuous pattern, occurs in innermost lining of the intestine. IBD can be debilitating and sometimes leads to life threatening complication[1].

ETIOLOGY

The specific etiology of IBD is unknown. A common hypothesis for the cause of IBD is that, it is the result of an unregulated intestinal immune response to environmental and bacterial triggers, probably in a host susceptible to genetic invasion.This response leads to the uncontrolled inflammation that causes damage to the gastrointestinal tract, resulting in symptoms[2] of homeostatic conditions, the innate and the adaptive immune systemsare balanced in complex interactions with intestinal microbes. In IBD, thishomeostasis is disrupted and uncontrolled intestinal inflammation is developed[3,4].

EPIDEMIOLOGY

The clinical spectrum of inflammatory bowel disease (IBD) is very wide and it may lead to life-threatening severe illness. Although the incidence of IBD is low, ranging from 2–15 per 100,000 for UC and 0.1–14 per 100,000 for CD, the economic costs to the patient and the state are high. IBD such as a chronic disorder, typically affect people during their younger age as well as the earning period of the life time which may require expensive medical and surgicalinterventions during the course of the disease. The onset in early adult life, the chronic nature of the disease, the need for a visiting clinician, laboratory tests, diagnostic procedures, hospitalisation and surgery all result in high costs for IBD patients with UC and CD. IBD also has significant adverse effects on the quality of life of patients suffering from it. The level of knowledge of IBD and quality of life are strongly interrelated, and a lower level of disease-related knowledge leads to more severe

impairment of the quality of life. Although some previous studies have shown that patient knowledge has no effect on Health Related Quality of Life (HRQOL), currently, there is evidence supporting the fact that the higher the level of disease-related knowledge, the better the HRQOL in IBD. Chronic diseases such as IBD require patient education in order to achieve adequate control and prevent adverse health outcomes[5].Disease-specific information is increasingly being recognized as important for patients as it improves compliance with therapy and satisfaction with their overall care[6,7].

CLINICAL FEATURES OF IBD PATIENTS

Symptoms may vary depending on the severity of inflammation and its occurrence. Symptoms may range from mild to severe and patients were likely to have periods of active illness followed by periods of remission. Signs and symptoms are common to both Crohn's disease and Ulcerative colitis.

- Diarrhea
- Fever and fatigue
- Abdominal pain and cramping
- Blood in stool
- Reduced appetite
- Unintended weight loss

RISK FACTORS

- Age
- Race
- Ethnicity
- Family history
- Cigarette smoking
- NSAIDS

COMPLICATION

- Colon Cancer
- Skin,eye joint infection
- Medication side effects
- Primary sclerosing cholangitis

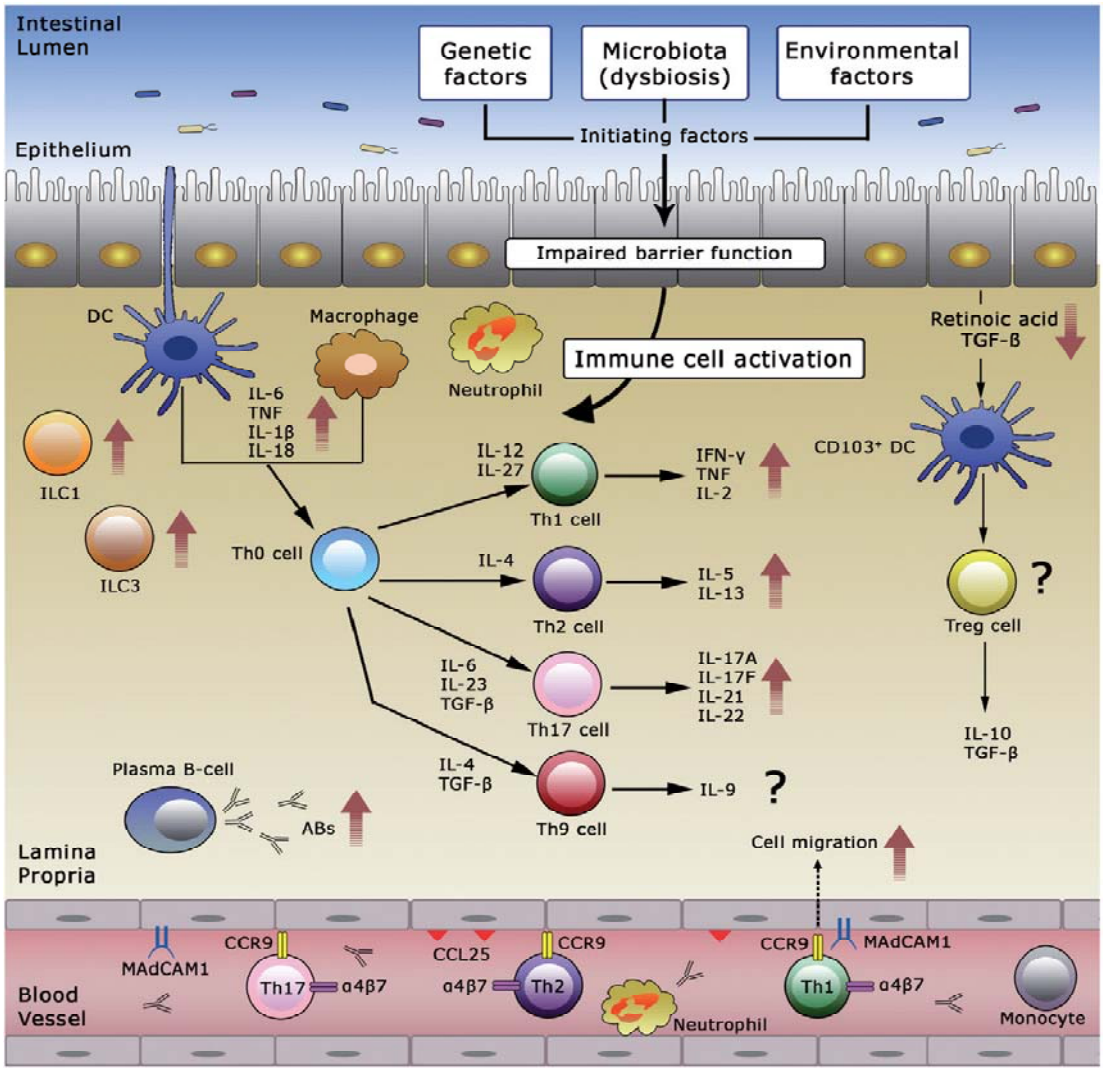
- Blood clots
- Bowel obstruction
- Malnutrition
- Ulcers, fistulas
- Anal fissures[9].

PATHOPHISIOLOGY

The most accepted hypothesis of IBD pathogenesis is that complex interactions between genetics, environmental factors, and the host immune system lead to aberrant immune responses and chronic intestinal inflammation. The human gut harbors a complex and abundant aggregation of microbes, collectively referred to as the gut microbiota. The gut microbiota has physiological functions associated with nutrition, the immune system, and defense of the host. Recent advances in next-generation sequencing technology have identified alteration of the composition and function of the gut microbiota, which is referred to as dysbiosis, in IBD. Clinical and experimental data suggest dysbiosis may play a pivotal role in the pathogenesis of IBD. This review is focused on the physiological function of the gut microbiota and the association between the gut microbiota and pathogenesis in IBD. In addition, we review the therapeutic options for manipulating the altered gut microbiota, such as probiotics and fecal microbiota transplantation. The gut microbiota in healthy individuals is known to provide a number of health benefits to the host, relating to pathogen protection, nutrition, metabolism, and the immune system. [10,11,12]

Immunopathogenesis of IBD: A dysregulated mucosal immune response is the central driver of IBD and is characterized by an altered innate immune system along with activated effector T-cells, an increased presence of B-cells and antibody production, as well as an increased production of pro-inflammatory mediators. Key innate and adaptive immune cells involved in IBD pathogenesis and cytokines produced by the various cell subsets in the affected mucosa are shown. The inappropriate activation and maintenance of inflammatory responses driven by cytokines and lack of control by reduced regulatory mechanisms and anti-inflammatory cytokines such as IL-10 and TGF-b lead to chronic intestinal inflammation. Furthermore, the inflamed intestine shows an increased expression of MAdCAM-1 leading to increased recruitment of gut-specific T-cells to the

LP and perpetuates the cycle of inflammation leading to chronic tissue injury and epithelial damage.[13]



KNOWLEDGE ASSESSMENT

Disease-specific information is increasingly beingrecognized as important for patients as it improvescompliance with therapy and satisfaction with theiroverall care.As can thus be expected, patients with a perceivedlack of disease-related information have poorerhealth-related quality of life than their peers, manifestedby higher frequency of disease-related worries andconcerns in this group Previousstudies have shown that patients who receive informationrelated to their disease are less anxious, more compliant,and more satisfied with their treatment and havea reduced number of

physician visits and lower patient cost.Appropriate knowledge and information enable for better quality of life in patients.[6]

QUALITY OF LIFE

HRQOL is generally defined as a multidimensional concept that incorporates the physical, emotional, and social features of health perception and health functioning. The diagnosis of a chronic medical disorder increases stress levels and introduces difficult changes, which, in turn, can alter HRQOL. For patients with IBD, such stressors may include abdominal discomfort, rectal bleeding, diarrhea, fecal urgency, impaired appetite, weight loss, and need for long-term (immunosuppressant) medication use, hospitalization, or surgery, among others. Thus, as with patients with other chronic diseases, it is not surprising that patients with IBD have poorer HRQOL compared to healthy controls.

Managing IBD poses challenges for the health-related quality of life (HRQoL) of affected youth. HRQoL is a multidimensional construct representing one's subjective assessment of the impact of one's health on physical and psychosocial functioning. Youth with IBD have lower HRQoL compared with healthy peers and poorer school-related HRQoL than healthy or chronically ill youth. Although patients suffering from these conditions have a normal life expectancy, the need for long-term medication, frequent hospitalizations, surgeries and the relapsing nature of the disease significantly negatively affect their quality of life (QOL)[6]

PATIENT EDUCATION

Patients with IBD are at risk for serious complications when their disease is poorly managed. Patient non-adherence to medical therapy contributes to suboptimal outcomes, but may be modified through improved education. Poorly controlled disease increases the risk for serious and often irreversible negative outcomes including death. Non-adherence to medical therapy may be associated with demographic factors such as gender (male) and marital status (single). Individuals may forego medical and/or surgical therapy due to inconvenience, costs, lack of understanding, or fear of side effects from therapy. Inconvenience and cost of therapy are difficult to address due to their limited

mutability, but fear of adverse effects from therapy and lack of understanding of available treatment options are factors that may be amenable to change. Education specific to IBD, its effects, and its management, can potentially increase patient adherence and improve outcomes for these patients. Current evidence suggests that many individuals with IBD lack the desired information about their disease. Specific areas of interest to IBD patients include: prevention and management of IBD symptoms, complications related to IBD, long term prognosis, risk of cancer and mortality, alternative therapies, risks from pharmacotherapy, potential new therapies, and fertility These information needs were identified through surveys administered to specific patient populations (e.g.newly diagnosed); however, to our knowledge an intensive qualitative study in a diverse IBD patient population specifically exploring this topic has not been published. This study is to determine the perceived educational needs of IBD patients (i.e. the information about issues that a patient desires to understand such as their disease process, prognosis, and therapeutic options), and to identify areas where providers believe patient understanding is critical. This information can be used to develop novel educational resources to facilitate patient adherence to therapy.[7]

Awareness is needed for chronic diseases like IBD to attain adequate control and require patient education in order to achieve adequate control and reduce harmful health issues. Disease based information has also a crucial role in helping patients to accept their health condition with an ease and to understand proper behavioral alterations that are needed in order to take part in the treatment effectively and also in enhancing the relationship of the doctor and patient.[8]

Need for assessing Knowledge and Quality of life

Disease related knowledge plays a vital role in facilitating patient's acceptance of their diagnosis and compliance with active participation in the treatment of Inflammatory Bowel Disease (IBD).The level in knowledge of IBD and quality of life are strongly inter-related, and a lower level of disease related knowledge leads to more severe impairment in the quality of life in IBD patients. Although some previous studies have shown that patient knowledge has no effect on Health Related Quality of Life (HRQOL) but currently there is a evidence supporting the fact that the higher the level of disease-

related knowledge, the better the HRQOL in IBD[13]. So there should be a furthermore advance study is essential to improve the patients' understanding of their disease. Lack of knowledge and understanding about IBD may impair a patient's ability to be an active participant in his/her own management. A working knowledge of their disease and its management is essential for patients with chronic disorders such as IBD. So a validated patient knowledge score for IBD has been developed and assessed, in relationship with HRQoL[14]. Additionally, disease related knowledge of IBD among patients may affect adherence to medications or coping skills, and hence affect HRQoL.

Chronic diseases such as IBD require patient education in order to achieve adequate control to prevent the adverse health outcomes.[15.] The patients should aware about the chronic nature of this disease if it is untreated or with the consequences of the disease when it persist. So it is very important to provide a better patient education for the awareness of the disease and their do's and dont's..There by patient may improve their quality of life in a healthy way[16,17,18]

There have only been a few studies that have assessed disease related knowledge in IBD,and that have been carried out in western countries.The incidence and prevalence indicating that the IBD is increasing gradually and the patient's knowledge about disease is very less.

The purpose of this study was, to determine the difference in disease related knowledge and information needs according to the general characteristics of IBD patients, then to improve the knowledge about the diseases and quality of life.

LITERATURE REVIEW

Chouliaras G et al.,(2017) conducted a cross sectional study to assess the impact of disease characteristics onthe quality of life (QOL) in children with inflammatorybowel diseases (IBD). The results of this study indicated that the disease activity is the major factor associated with low QOL in children with IBD. This study demonstrated that disease activity is the main correlation of quality of life (QOL) in children. Several factors, that increased risks for impaired QOL for children with IBD, were identified. So the children of younger age, the early years after the diagnosis and the presence of extra-intestinal manifestations were inversely related to IMPACTIII scores. Therefore, in children with these specific features, physicians should be more vigilant in order to recognize and address issues related to their QOL promptly[17].. **Soobraty A *et al*.,(2017)** conducted a survey on current practice of clinicians regarding medication non-adherence in patients with Inflammatory Bowel Disease.Respondents stated forgetfulness, beliefs about necessity of medication and not immediately apparent benefits as the main reasons for non-adherence. Patient counselling on benefits and risks of medication was a commonly used intervention.They concluded that urgent need for further clinician education on non-adherence and robustly tested interventions that are capable of improving adherence.[19]

Reghu *et al*.,(2017) conducted a prospective, interventional follow up study to evaluate clinical pharmacist's interventions have any impact on medication adherence of patients having inflammatory bowel disease and to assess the awareness of patients about their disease and the significance of medications they use. They concluded that proper education program has a good effect on patients to improve their knowledge level on ibd[20].

Chen *et al* .,(2017) done a study to identify the environmental risk factors that are associated with IBD. Several environmental factors, such as smoking, appendicitis, OCPs, diet, breastfeeding, infections/ vaccinations, antibiotics, helminths, and childhood hygiene, have been implicated in the increased worldwide incidence of IBD. But the most consistently demonstrated environmental risk factor, smoking, contributes only partially to disease pathogenesis (ie, most smokers do not

have CD and most CD patients do not smoke). Thus, further studies are necessary to better understand the environmental determinants of IBD[21].

Velonias et al (2017) done a study to analyse health related quality of life in older age. They resulted that Older age patients was associated with modestly higher SIBDQ and mental HRQoL but lower physical HRQoL. Comprehensive care of the older IBD patient should include assessment of factors impairing physical quality of life to ensure appropriate interventions[22].

L.Dibley *et al.*,(2017) done a study to identify the research priorities for the nursing of inflammatory bowel disease patients. And they concluded that these research priorities have a good impact on the nursing of IBD patients[23].

Anna catarena.,et al (2017) conducted a study to observe a relation between appendectomy and IBD, crohns disease. And found out that transient increased risk of Crohn's disease after an appendectomy was probably explained by diagnostic bias.[24]

Wheat C. L. *et al.*,(2016) conducted a study to identify educational needs, and barriers and factors associated with non-adherence among inflammatory bowel disease (IBD) patients.Eighteen IBD patients and ten IBD providers were recruited. Semi-structured interviews were conducted and a qualitative framework approach used to identify patient educational needs, barriers to obtaining information, and factors associated with non-adherence with medical therapy. They concluded that there are several deficits in knowledge in IBD patients and they identified factors associated with IBD patient comprehension, decision making, and non-adherence to therapy. These results can be used to develop targeted educational resources to improve adherence among IBD patients and they propose that patient self-management programs are potentially effective educational interventions that warrant further study in IBD[25].

A. A. El. Mahalli, H.M. Ali Alharthi *et al.*,(2016) done a study to assess the health related quality of life of patients with inflammatory bowel disease. They concluded as relapse,long duration of disease (<5yrs),low education and young age at disease onset may entail increased risk for decreased HRQOL.[26]

Sasha Taleban et al.,(2016) conducted a study to examine the correlation between QOL and clinical activity indices and endoscopic disease activity according to disease characteristics. data suggest good correlation between SCCAI and endoscopic disease activity in UC, particularly in left-sided disease. Poor correlations between HBI or SIBDQ and SES-CD appear to be consistent across different disease phenotypes.[27]

Hou JK et al.,(2015) conducted a prospective study to evaluate the association between patient disease knowledge of inflammatory bowel disease (IBD) and health related quality of life (HRQoL) and identify patient and disease related predictors of patient knowledge of IBD. IBD diagnosis at a younger age in addition to Caucasian race and higher education were significantly associated with higher knowledge about IBD. However, patient knowledge of IBD was not correlated with HRQoL. Further studies are required to study the effect of patient knowledge of IBD on other clinical outcomes.[18]

Zhang YZ *et al*.,(2014) done a study about the pathogenesis and and the risk factors about the disease. They found out that the key factors responsible for IBD include genetic components, environmental elements, microbial flora and immune responses. It is hard to dispute the popular belief that IBD arises from an extremely complex interaction among genetic and environmental elements, dysregulated immune responses and alterations of the microbiome, and that none of these factors alone is likely to cause the disease. The growing number and diversity of genetic loci associated with IBD provide major challenges to the investigation of how they impact immunity and inflammation in susceptible individuals. Future research needs to further clarify and integrate the effects of the microbiome and environment on the immune response, and it shall be essential to gain further insights into the mechanisms and pathways of how bacteria, viruses or even fungi can modulate innate and adaptive immune responses.[1]

Huppertz-Hauss et al.,(2015) conducted a study to evaluate the HRQoL in European patients with ulcerative colitis and Crohn's disease,10 years after diagnosis

(European Collaborative study group of Inflammatory Bowel Disease) compared with the national background population in each country and to assess possible country-specific differences. Patients with IBD from 7 European countries were included in the study and done a follow-up visit 10 years after their diagnosis of IBD. They assessed their clinical and demographic data, including the generic HRQoL questionnaire short form health survey-36.They concluded that the HRQoL was not reduced in the IBD cohort compared with the background populations and old age, female gender, current symptoms at follow-up, disablement pension, and sick leave during the previous year were significantly associated with a reduced HRQoL in patients with IBD[31].

S. Lonnfors et al.,(2014) done a survey on patients with IBD to analyse the impact of IBD in their health related quality of life and obtaining a better understanding of the quality of care, assess to care. The result of this survey present a large up to date, high quality data set and this data can be used for the furthermore unmet needs of IBD patients for their awareness.[47]

Ananthakrishnan *et al.*,(2014) done a study to find out the various trigger factors for the development of IBD. This study shows that Lower plasma vitamin D is associated with anincreased risk of Crohn's disease, and vitamin D supplementation may prevent relapse of disease.There is continuing evidence that depression and psychosocialstress may play a role in the pathogenesis of both CD and UC, while at the same time alsoincreasing risk for disease flares. There is also a growing understanding of the role of diet on IBD,in particular through its effect on the microbiome. There is need for routine measurement of aspectrum of environmental exposures in prospective studies to further our understanding.

Joana Magalhaese et al.,(2014) done a study to analyze the relationship between clinical and sociodemographic factors and quality of life in inflammatory bowel disease patient. They found out that the decrease in HRQL was significantly related with personal perception of a lower disease impact in success and social

relations. These factors deserve a special attention, so timely measures can be implemented to improve the quality of life of patients.[32]

J. Burisch et al(2014): in a population based study to assess and validate the pattern of HRQoL in an unselected, population-based inception cohort of IBD patients from Eastern andWestern Europe. Medical and surgical treatment improved HRQoL during the first year of disease. They concluded that the majority of IBD patients in both Eastern and Western Europe reported a positive perception of disease-specific but not generic HRQoL. Biological therapy improved HRQoL in CD patients, while UC patients in need of surgery or biological therapy experienced lower perceptions of HRQoL than the rest.

Irina Blumenstein et al.,(2013) conducted a study to assess sources of information and patient knowledge in Irish and German inflammatory bowel disease patients. they found out that German patients obtained knowledge from a wider range of sources than Irish patients and few differences between German and Irish IBD patients, despite cultural and linguistic differences, with regard to disease related knowledge of IBD[33].

Amitha Prasad Gumidyala et al.,(2013) done a cumulative risk model approach to examine cross-sectional relationships among several potential risk factors and HRQoL in a sample of youth with IBD using the CRM framework. They hypothesized that a higher number of risk factors would be associated with lower youth HRQoL total scores, as well as lower HRQoL scores in the physical and psychosocial health domains. Overall, their findings offered support for the value of the CRM in explaining variance in HRQoL of youth with IBD. The CRI was associated with all youth- and mother-reported HRQoL domains. Furthermore, contextual domain factors were most consistently associated with youth and maternal reports of HRQoL. These results show promise in supporting the value of the CRI in identifying potential risk factors for lower HRQoL in a cross-sectional sample[34].

A. Moradkhani et al.,(2013) conducted a study on 134 patients. Individuals with IBD who report higher perceived stress, lower perceived social support, greater

number of relapses, or are female may be at increased risk for decreased HRQOL. Prospective studies should investigate how interventions addressing these factors may lead to improved HRQOL.[28]

C.P. Selinger *et al.*,(2012) conducted a study to identify predictors of anxiety in IBD and examine the interplay between anxiety and disease-related patient knowledge and The effect of anxiety on quality of life was also explored. Disease-related knowledge was assessed using thevalidated Crohn's and Colitis Knowledge score (CCKnow) and disease related QOL using the short IBD questionnaire (SIBDQ). Anxiety anddepression were assessed with the Hospital Anxiety and Depression Scores. Of the 258 patients 19.4% had a potential anxiety and a further 22.4% had a probable anxiety disorder. The study concluded that disease related quality of life was significantly lower in patients with anxiety and an educational intervention may not necessarily reduce anxiety. Further work is needed to evaluate the association between anxiety and knowledge and to develop targeted interventions that will improve knowledge and simultaneously reduce anxiety.[36]

Lars-Petter Jelsness-Jørgensen et al.(2012)conducted a study to assess the disease relatedworries and concerns among IBD patients prospectively for one year. And the IBD-related worries associated with Socio demographicand clinical data. In addition, they evaluated the psychometric properties of the Norwegianversion of the RFIPC.They found out that the pattern of worries in IBD is relatively consistent over a period of one year. However, the level of worries, as measured with the RFIPC, increased successively with IBD symptoms. Their findings might indicate that the current IBD symptoms that are important for the level of worrying and not a history of serious events in the past.[35]

Keefer et al.(2012) done a study to develop a valid and reliable measure of IBD-specific Self Efficacy Scale that can be used in clinical and research contexts. And in their study,122 adults with a verified IBD diagnosis were participated. They concluded that 29-item IBD-SES has high internal consistency (r= 0.96), high test-retest reliability (r = 0.90), and demonstrates strong construct and concurrent validity with established measures. The IBD-SES was a critical first step towards addressing

an important psychological construct that could influence treatment outcomes in IBD.[37]

Fabiana clastiglione et al (2012).,done a prospective observational study to evaluate risk factors for IBD related to HH in a cohort of IBD patients.We investigated the main surrogate markers of HH (helmintic infections and antibiotics in childhood; breastfeeding; family size/sibship; urban upbringing; personal and domestic hygiene in childhood) in UC and CD patients, in comparison with a control group of healthy subjects. In addition, the traditional risk factors for IBD were also recorded. Familial aggregation, smoking habits and appendectomy still remain the main risk factors associated with IBD[38].

Samaraskera *et al.*,(2010) conducted a study on 184 patients to analyse the disease related knowledge in inflammatory bowel disease which was conducted in a tertiary care centre in a developing country in South Asia. The aim of this study was to analyse the deficits in knowledge for future health education programmes. There is a lack of knowledge regarding colorectal cancer risk and surgical interventions. There was no significant difference in the knowledge scores between genders but there was a significant association with the educational level[39.]

Mikocka Walus et al.,(2008) done a observational study to compare the clinical outcomes in relation to psychological co-morbidity in patients with inflammatory bowel disease (IBD), irritable bowel syndrome (IBS) and chronic hepatitis C (HCV) and to assess the psychological co-morbidities that are related with these diseases. They concluded that there was no significant relation between the psychological problems at baseline and clinical outcomes so further studies needed for better understanding[40].

Waters et al.,(2005) conducted a study on 65 patients The purpose of the present study was to evaluate the effects of a formalized education program on patients with IBD. Assessment of IBD knowledge and QOL occurred at baseline, immediately posteducation and eight weeks posteducation. Participants documented medication adherence and health care use in diaries. Patient satisfaction was assessed

at the end of the study. The formal IBD patient education program improved knowledge, perceived knowledge and patient satisfaction. Positive trends toward greater medication adherence and lower health care use were demonstrated.. The current study shows that there is a great impact on education program on their increased quality of life.[41]

Kaplan, Pedersen, Andersson, et al.,(2007) done a population-based cohort study in Swedenand Denmark to assess the risk of developing Crohn's disease after an appendectomy and they concluded that the transient increased risk of Crohn's disease after an appendectomy is probably explained bydiagnostic bias.[46]

J. Burisch et al., (2014) done a study to assess and validate the patternof HRQoL in an unselected, population-based inception cohort of IBD patients from Eastern andWestern Europe. They found out that Medical and surgical treatment improved HRQoL during the first year of disease and the majority of IBD patients in both Eastern and Western Europe reported a positive perceptionof disease-specific but not generic HRQoL. They also resulted that biological therapy improved HRQoL in CD patients,while UC patients in need of surgery or biological therapy experienced lower perceptions ofHRQoL than the rest.

AIM AND OBJECTIVES

AIM:

To study the deficits of disease specific knowledge in IBD patients and to improve their health related quality of life.

OBJECTIVES:

- To analyse the disease related factor associated with IBD knowledge.
- To prepare patient information leaflet for IBD.
- To identify the knowledge deficits and to provide interventional patient education.
- To compare the difference in knowledge of IBD Patients.
- To assess the association between IBD knowledge and Health Related Quality of Life (HRQoL).

METHODOLOGY

STUDY DESIGN:

Aprospective observational study on knowledge assessment and quality of life of IBD patients. Assessment of knowledge and quality of life was done in their pre visit and PILS were provided inorder to make them better understanding. On their post visit knowledge and quality of life were re assessed and the difference were analysed.

STUDY SITE:

The study was conducted at the Department of Gastroenterology, Kovai Medical Center and Hospital,(KMCH) at Coimbatore.

STUDY PERIOD:

The study was conducted from the period from February 2018to July 2018.

STUDY POPULATION:

A total of 74 IBD patients were included in this study,

STUDY CRITERIA:

INCLUSION CRITERIA:

- Patients aged between 20 - 80 years of both genders (male and female).
- Patients diagnosed with IBD
- Atleast one prior outpatient clinic visit with gastroenterologist.

EXCLUSION CRITERIA:

- The patients having lack of cooperation and diagnosed mental illness.
- Being too ill to participate.
- Pregnant womens were excluded.

SOURCES OF DATA:

A specially designed data collection form will be utilized to collect patient's demographic details, past and present medical conditions, psychological factors, clinical features, intestinal manifestation and all other details required for the study.

STUDY TOOLS

- Patient proforma
- CCKNOW scale(for monitoring knowledge)
- PILS
- SIBDQ(to assess the quality of life)
- Patient satisfaction**.**

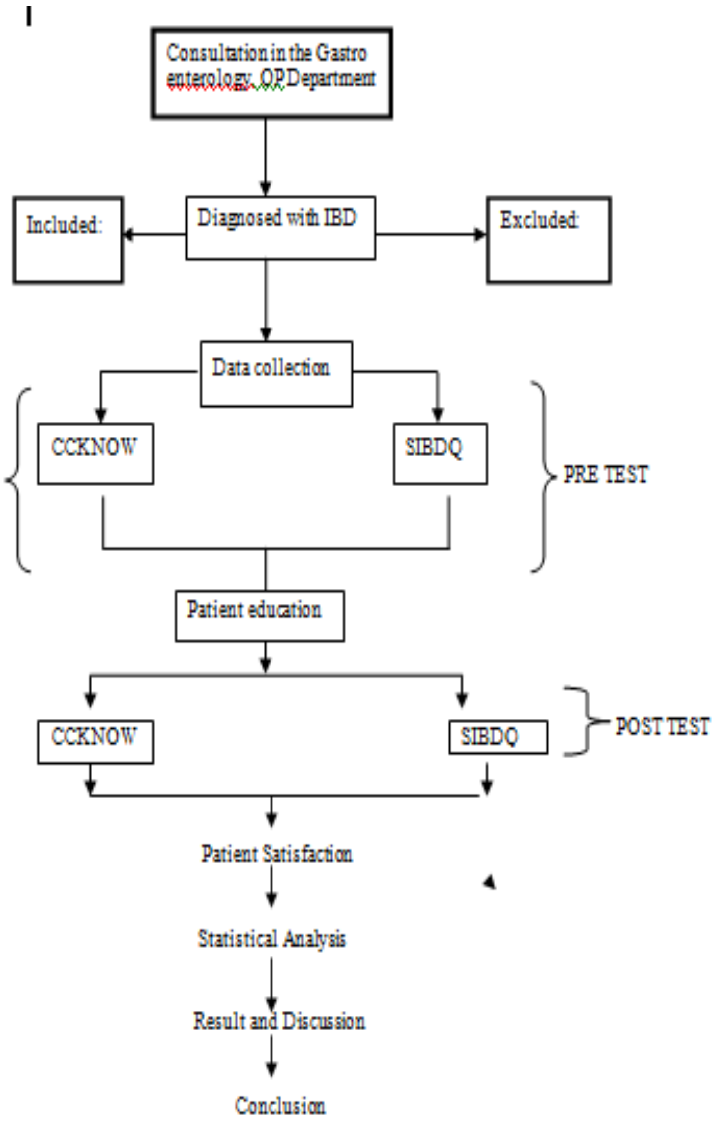
STUDY PROCEDURE

Inflammatory bowel disease (IBD), chronic inflammatory condition of the gastrointestinal tract resulting in a marked decrease in health related quality of life. Patients with IBD often experience remission and alternating with periods of disease activity (relapse). Although the patient suffering fromthese conditions will have a deficits in disease related knowledge and there by affects their quality of life. So adequate knowledge about the disease may improve their quality of life.

Literature review; an extensive literature survey was done on different aspects in knowledge and quality of life of patients. The literatures supporting the study was collected from various journal like World journal of Gastroenterology, Journal of young pharma, Singapore International journal etc.

Ethical committee approval for conducting the study in the hospital was obtained from the chairman, Kovai Medical Center and Hospital, Coimbatore on 10th of February.

Participant Flow Chart



PHASE – I
(FEB – APRIL 2018

PHASE –II
(APRIL – MAY 2018

PHASE –II
(MAY – JULY 2018

STUDY PROTOCOL:

The study was carried out after the approval from the Ethical Committee of the hospital on 10th February 2018. The patients who diagnosed by IBD were included in the study. 74 patients were included in the study. The essential data were collected using data collection form. Patients were interviewed with CCKNOW and SIBDQ

questionnaire. All the patients were counselled and provided with patient information leaflet regarding the disease. After 4-5 weeks these patients were interviewed again with these CCKNOW and SIBDQ questionnaire.

KNOWLEDGE ASSESSMENT

Knowledge assessment was done by Crohns And Colitis Knowledge Assessment Score(CCKNOW). The CCKNOW scorewas selected because it has a valid index of high internalconsistency. It also has a high reliability that assesses thedisease-related knowledge of IBD patients in four specificknowledge areas with regard to the management of IBD.These include a general understanding of the disease (12questions), diet (2 questions), treatment (5 questions) andcomplications (5 questions). One point was awarded foreach correct answer and there were no negative marksfor incorrect answers, with a maximum possible scoreof 24 for all questions. Each patient in this study was given a knowledge score in their pre visit and post visit of my study.

QUALITY OF LIFE ASSESSMENT

TheSIBDQ uses 10 questions derived from the original 32item full Inflammatory Bowel Disease Questionnaireto subjectively assess the HRQoL in patients withIBD. The SIBDQ examines four domains: bowelsymptoms, systemic symptoms, emotional function,and social function. Each question is scored from 0 to7 with a total score ranging from 10 (worst health) to70 (best health).

STATISTICAL ANALYSIS

Statistical Analysis was done by using SPSS (statistical package for the social science) version 16. Socio demographic characteristics were compared before and after intervention between the knowledge scores by chi square test. The mean values of the scores before and after intervention and QoL were calculate by paired ttest. The mean scores of each domains of SIBDQ with socio demographic were assessed by ANOVA.

TABLES AND FIGURES

Table1:Age Wise distribution of total Study Population(n=74)

Sl.No	Age(yrs)	UC (36)	CD (38)
		%	%
1	20-40	17(22.9)	17(22.9)
2	41-60	14(18.92)	14(18.92)
3	61-80	5(6.76)	7(9.46)

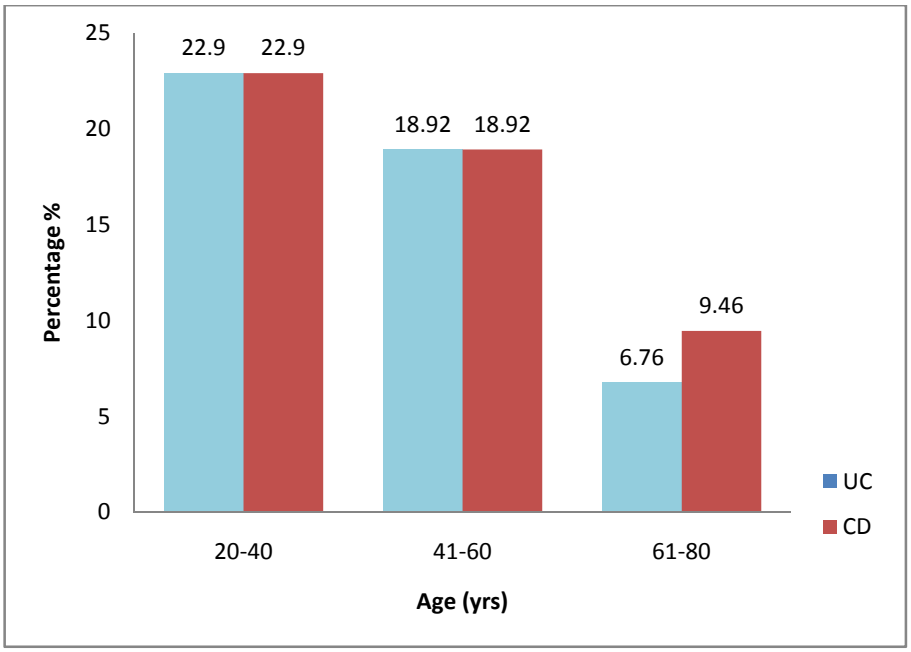


Fig 1: Plot for Age wise distribution of total study population

Table 2:Gender Wise Distribution of Study Population (n=74)

Sl.No	Gender	UC (36)	CD (38)
		%	%
1	Male	21(28.38)	16(21.62)
2	Female	15(21.62)	22(29.73)

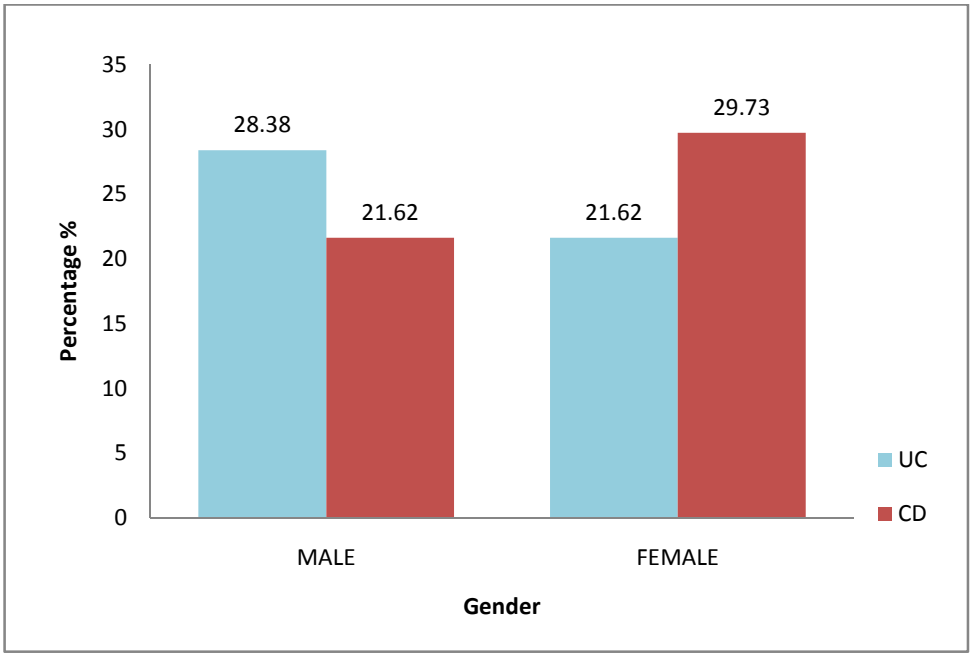


Fig 2: Plot for Gender wise distribution of study population

Table 3:Clinical Features of Study Population(n=74)

Sl.No	Complaints	UC(n=36)	CD (n=38)
		%	%
1.	Abdominal pain	20(27.03%)	25(33.78%)
2.	Loose stool	10(13.51%)	6(8.11%)
3.	Weight loss	1(1.35%)	5(6.75%)
4.	Blood in stool	5(6.76%)	2(2.70%)

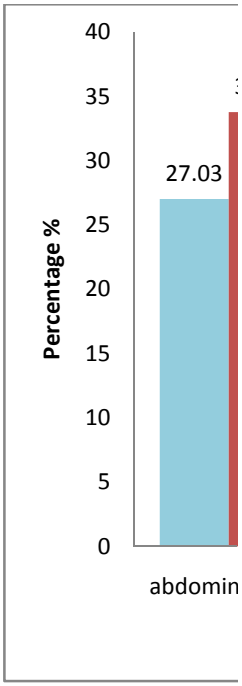


Fig 3: Plot for Clinical features of study population

Table 4: Past history Of Patients (n=74)

Sl.No	Past History	UC (36)	CD (38)
		%	%
1.	NIL	20(27.03)	19(25.68)
2.	DM	5(6.76)	6(8.11)
3.	HTN	3(4.05)	0(0)
4.	INTESTINAL DISORDER	0(0)	1(1.35)
5	IBD	2(2.7)	7(9.46)
6	OTHER	6(8.11)	5(6.76)

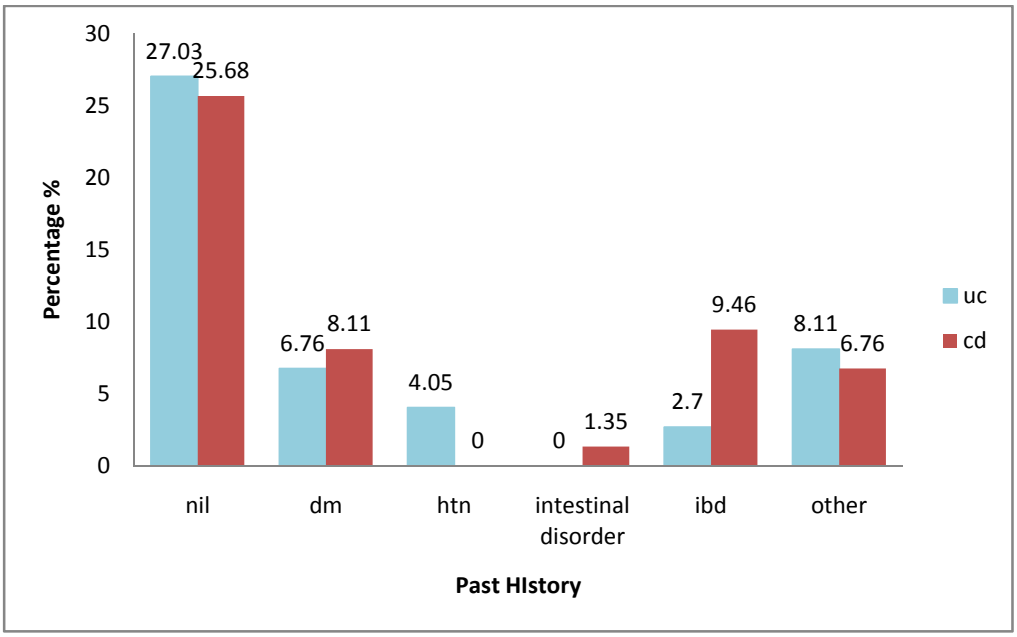


Fig 4:: Plot for Past history of Patients

Table:5 Distribution of surgery patients among study population(n=74)

Sl.No	SURGERY	UC (36)	CD (38)
		%	%
1	YES	9(12.16%)	17(16.49%)
2	NO	27(22.97%)	21(28.38%)

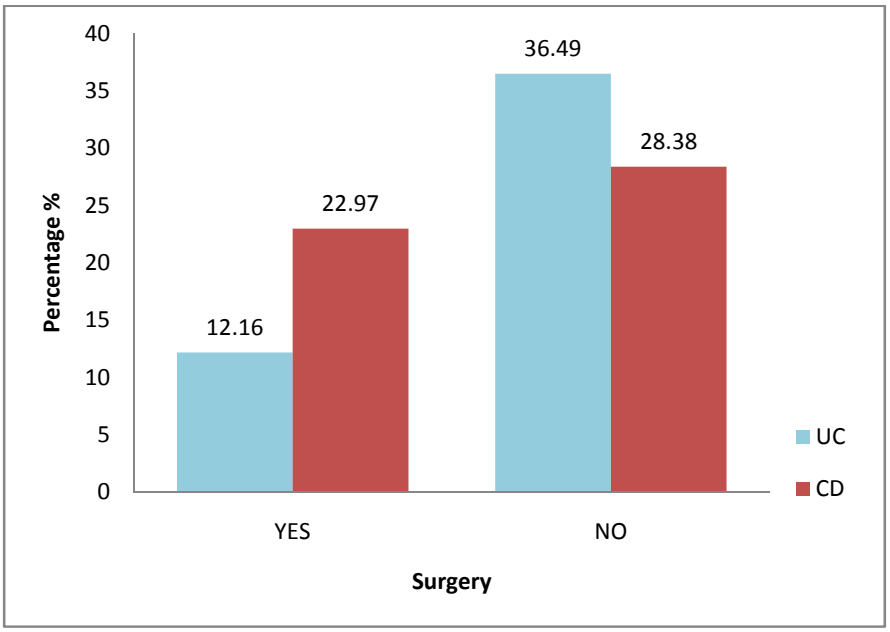


Fig5 Distribution of surgery patients among study population

Table: 6 Distribution of Appendictitis Patients(n=74)

Sl.No	APPENDICITIS	UC (36)	CD (38)
		%	%
1.	YES	6(8.11%)	6(8.11%)
2	NO	30(40.54%)	32(43.24)

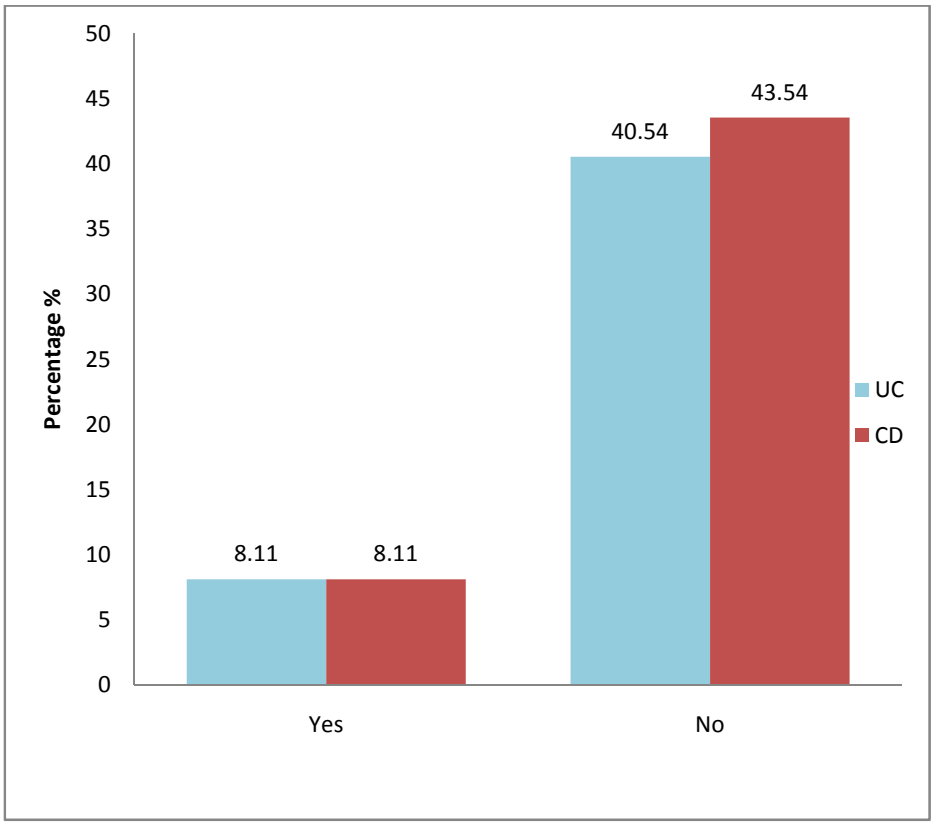


Fig 6: Distribution of Appendictitis Patients

Table:7 Type of food habits among total study population n=74

Sl.No	Food Habits	UC (36)	CD (38)
		%	%
1.	Vegetrian	5(6.76)	7(9.46)
2.	Non Vegetarian	31(41.89)	3141.89

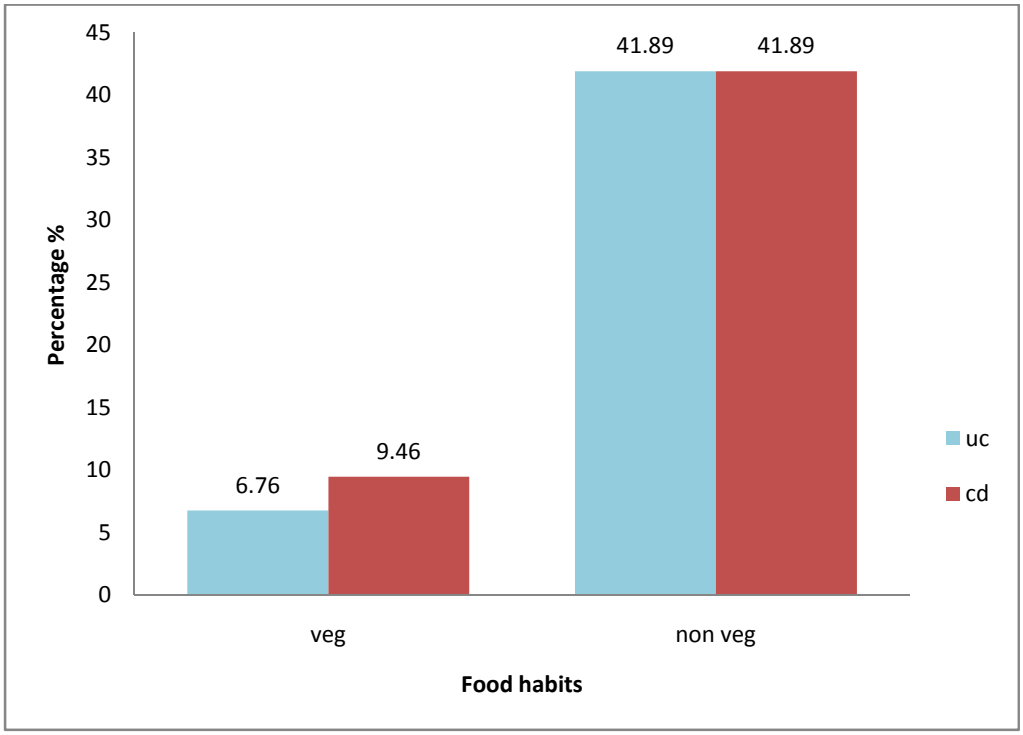


Fig 7:Type of food habits among total study population n=74

Table: 8 Psychological factors among total study population n=74

Sl.No	PHYCHOFACTORS	UC (36)	CD (38)
		%	%
1	STRESS	33(44.5)	36(48.65)
2	EMOTION	3(4.05)	2(2.70)

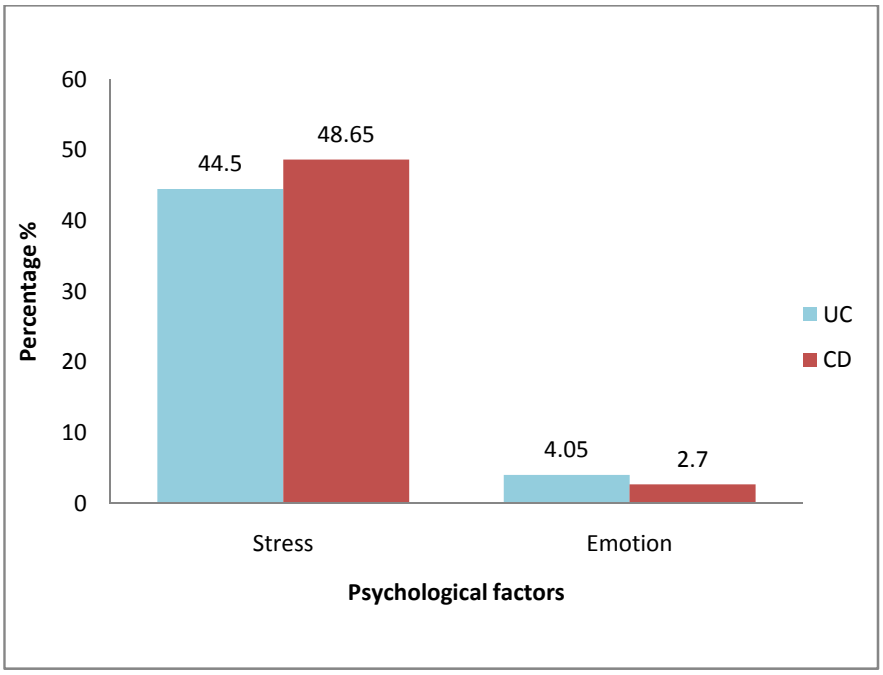


Fig 8:Psychological factors among total study population n=74

Table:9 Life style habits among study population=74

Sl.No	Life style habits	UC (36)	CD (38)
		%	%
1	Coffee	26(35.14)	(33.78)
2	Tea	9(12.16)	13(17.57)
3	Alcohol	1(1.35)	0

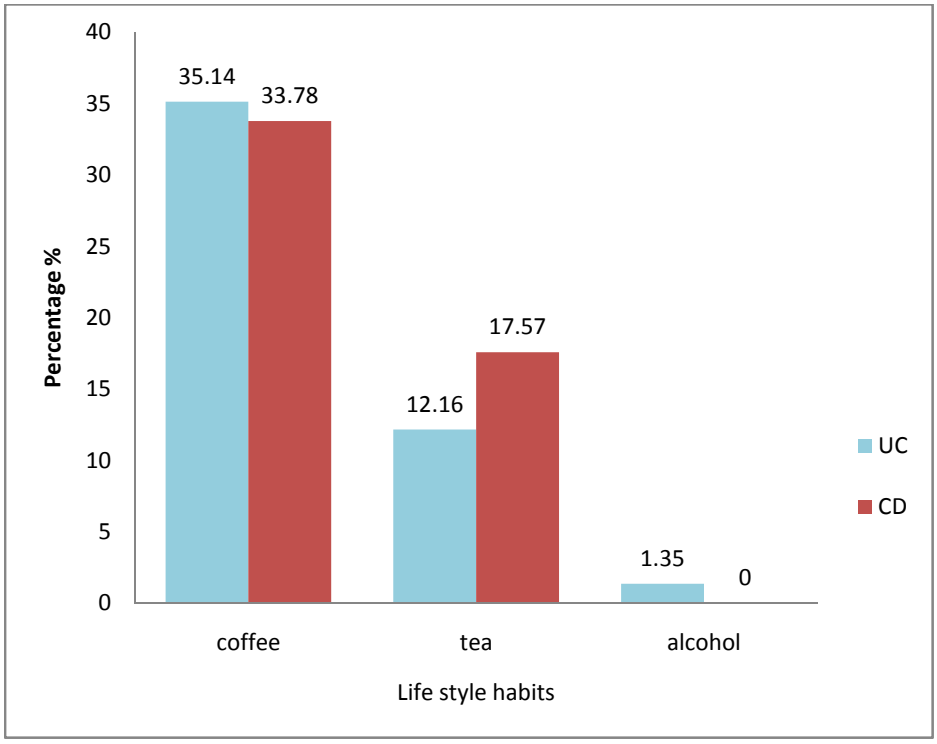


Fig 9: Life style habits among study population=74

Table 10. Newly diagnosed patients among study population(n=74

Sl.No	Newly Diagnosed Ptients	UC (36)	CD (38)
		%	%
1.	YES	19(25.68%)	17(22.97%)
2	NO	17(22.97%)	21(43.24)

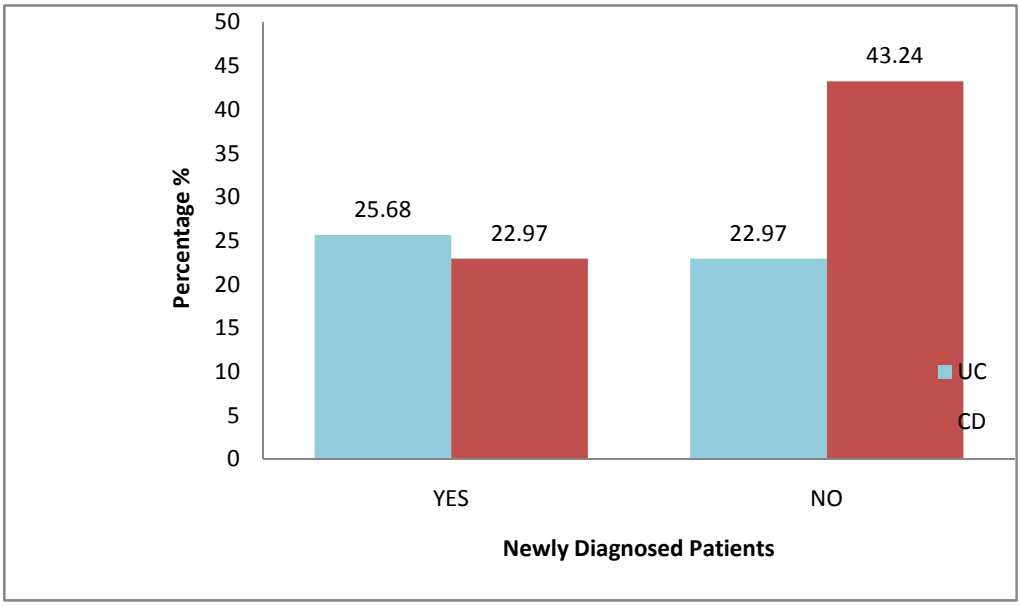


Fig 10: Plot for Newly diagnosed patients among stusy population (n=74)

Table 11: Duration of IBD among study population (n=74)

Sl.No	Duration of IBD	UC (36)	CD (38)
		%	%
1	1-6 (mnths)	19(25.68)	13(17.57)
2	7-12(mnths)	0	2(2.70)
3	>1 yr	10(13.51)	17(22.97)
4	Nil	7(9.46)	6(8.11)

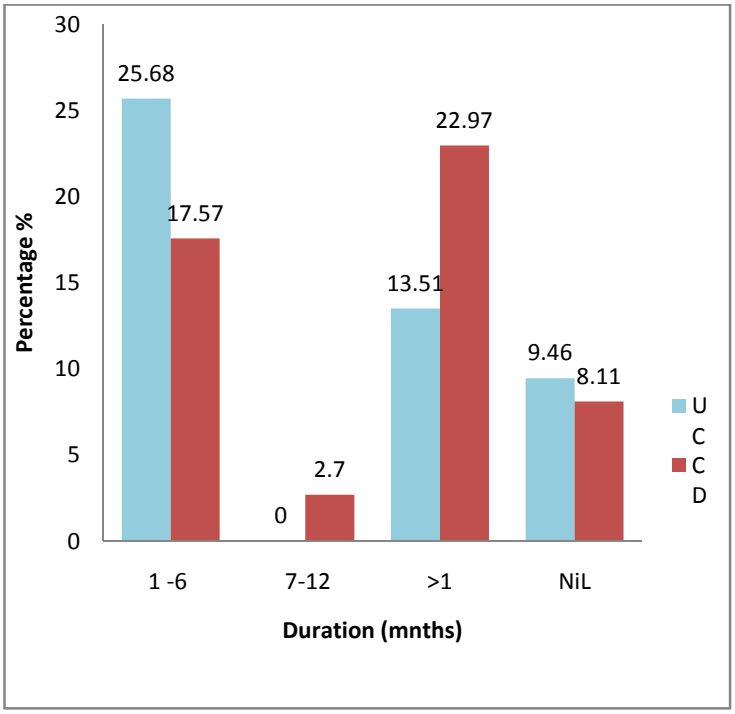


Fig 11: Plot for Duration of IBD among study population(n=74)

Tabk 12: Hospitalisation among total study population

Sl.No	Hospitalisation of patients	UC (36)	CD (38)
		%	%
1	Yes	4(5.41%)	2(2.70%)
2	No	21(28.38%)	17(22.97%)
3	>1	11(14.86%)	19(25.68%)

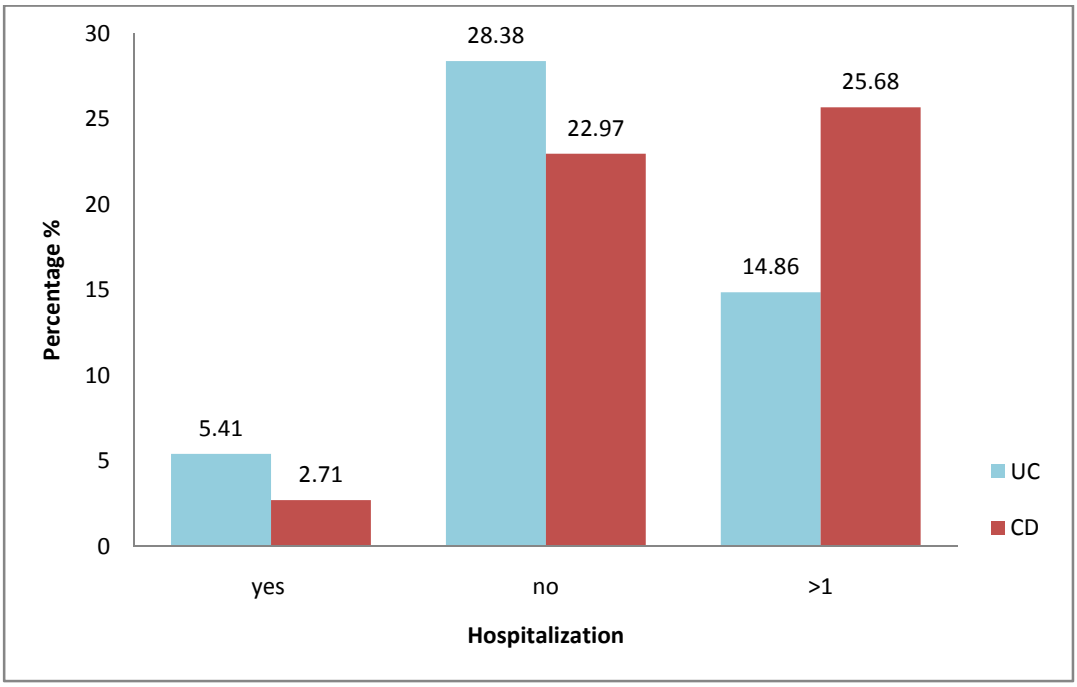


Fig 12: Plot for Hospitalisation among total study population

Table 13: Clinical Manifestation among the study population (n=74)

Sl.No	Clinical Manifestation	UC (36)	CD (38)
		%	%
1	Arthralgia	7(9.465)	9(2.16%)
2	Bach ache	3(4.05%)	4(5.41%
3	Skin lesion	0	1(1.35%)
4.	Hepato biliary	0	1(1.35%)
5.	Nil	26(35.14%)	23(31.08%)

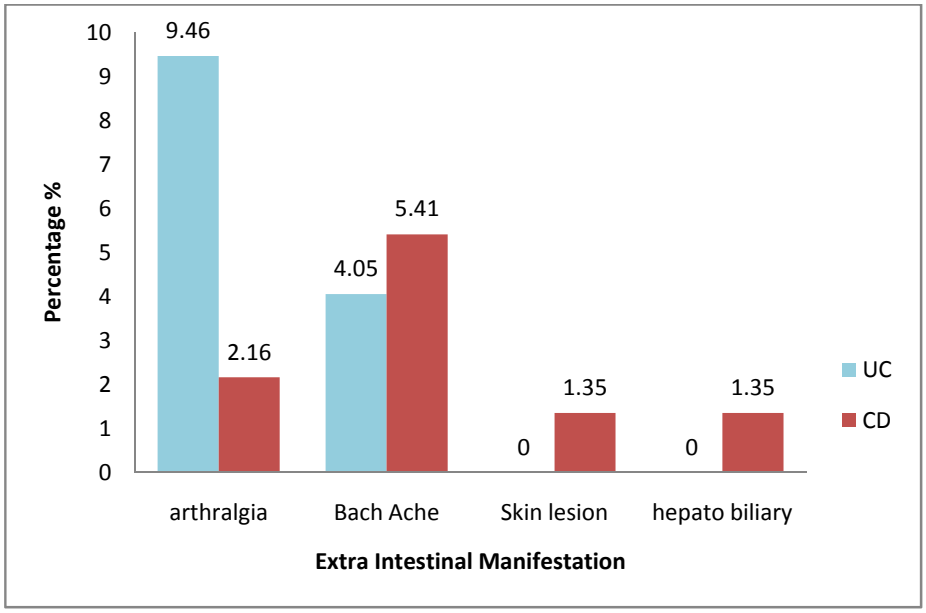


Fig 13:Clinical Manifestation among the study population (n=74)

Table 14:Localisation of the inflammation among the study population (n=74)

Sl.No	Localisation	UC (36)	CD (38)
		%	%
1	Proctitis	12(16.22%)	0
2	Left colon	9(12.11%)	0
3	pancolitis	15(20.27%)	0
4.	ileal	0	12(16.22%)
5.	ileocolonic	0	19(25.62%)
6.	colonic	0	7(9.11%)

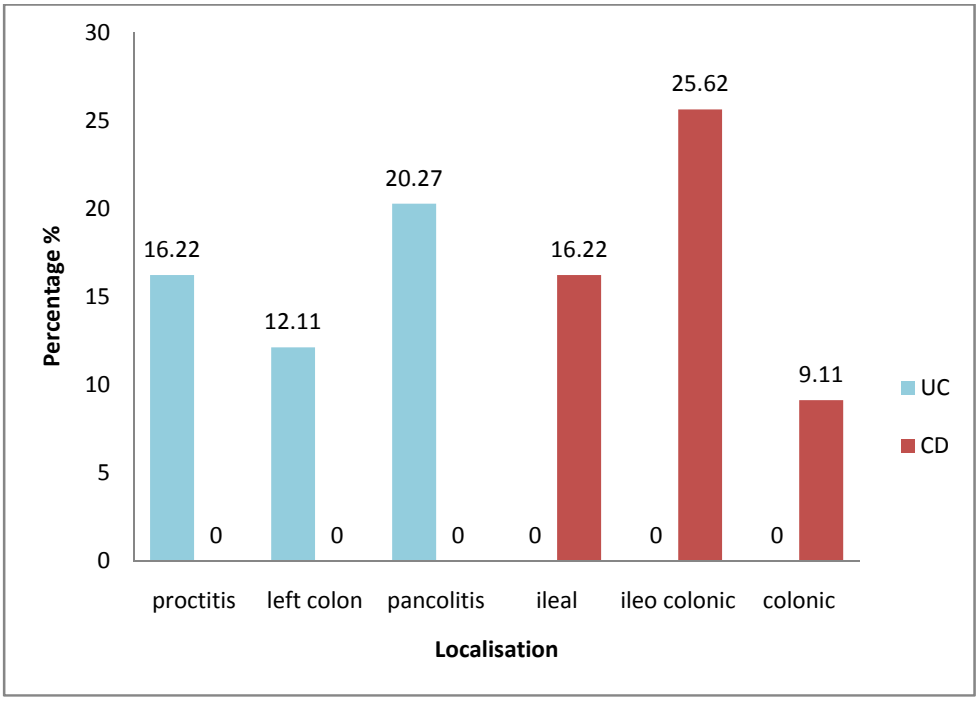


Fig 14 :Localisation of the inflammation among the study population (n=74)

Table 15: Relapsed patient among study population

Sl.No	Relapsed Patients	UC (36)	CD (38)
		%	%
1.	YES	2(2.70%)	9(12.16%)
2	NO	34(45.95%)	29(39.19%)

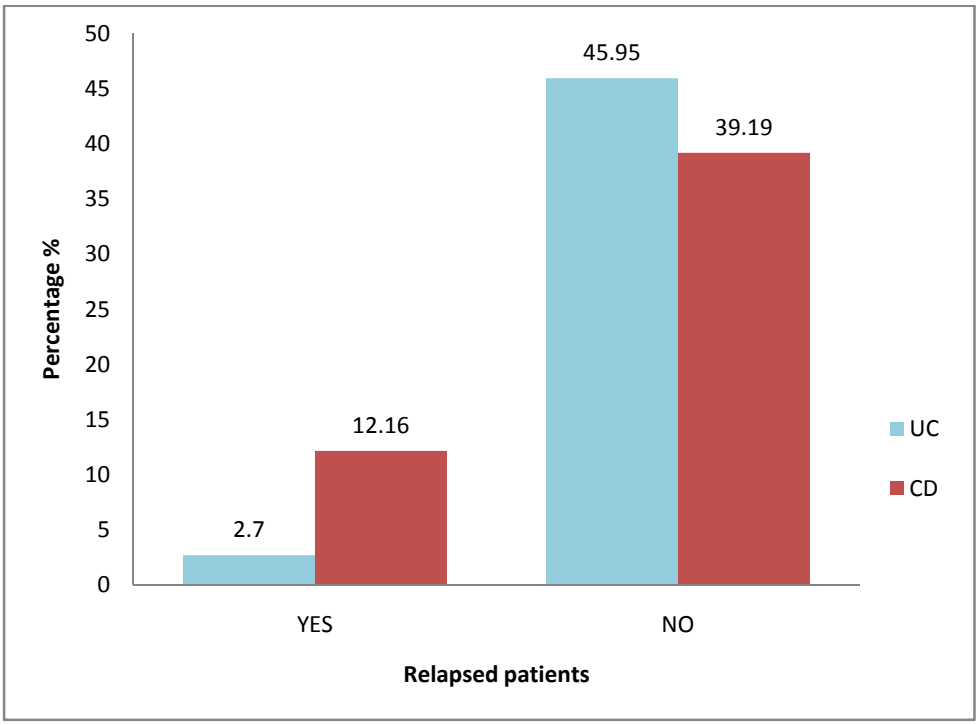


Fig 15: Relapsed patient among study population

Table 16: Family History among study population

Sl. No	Family History	UC (36)	CD (38)
		%	%
1.	YES	2(2.70%)	9(12.16%)
2	NO	34(45.95%)	29(39.19%)

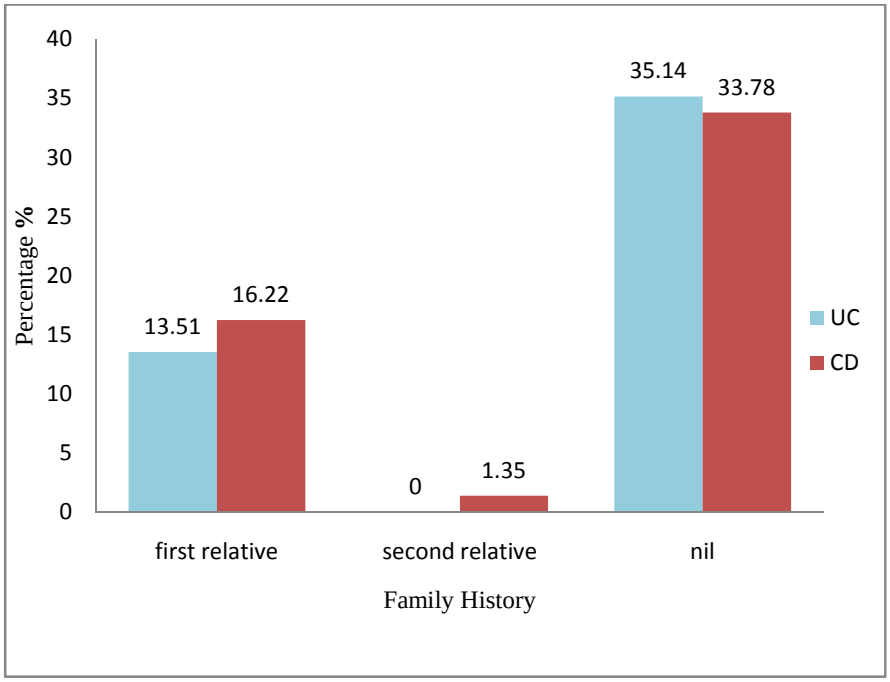


Fig 16: Family History among study population

PERCENTAGE OF CORRECT ANSWERS FOR CCKNOW QUESTIONNAIRE BEFORE AND AFTER VISIT

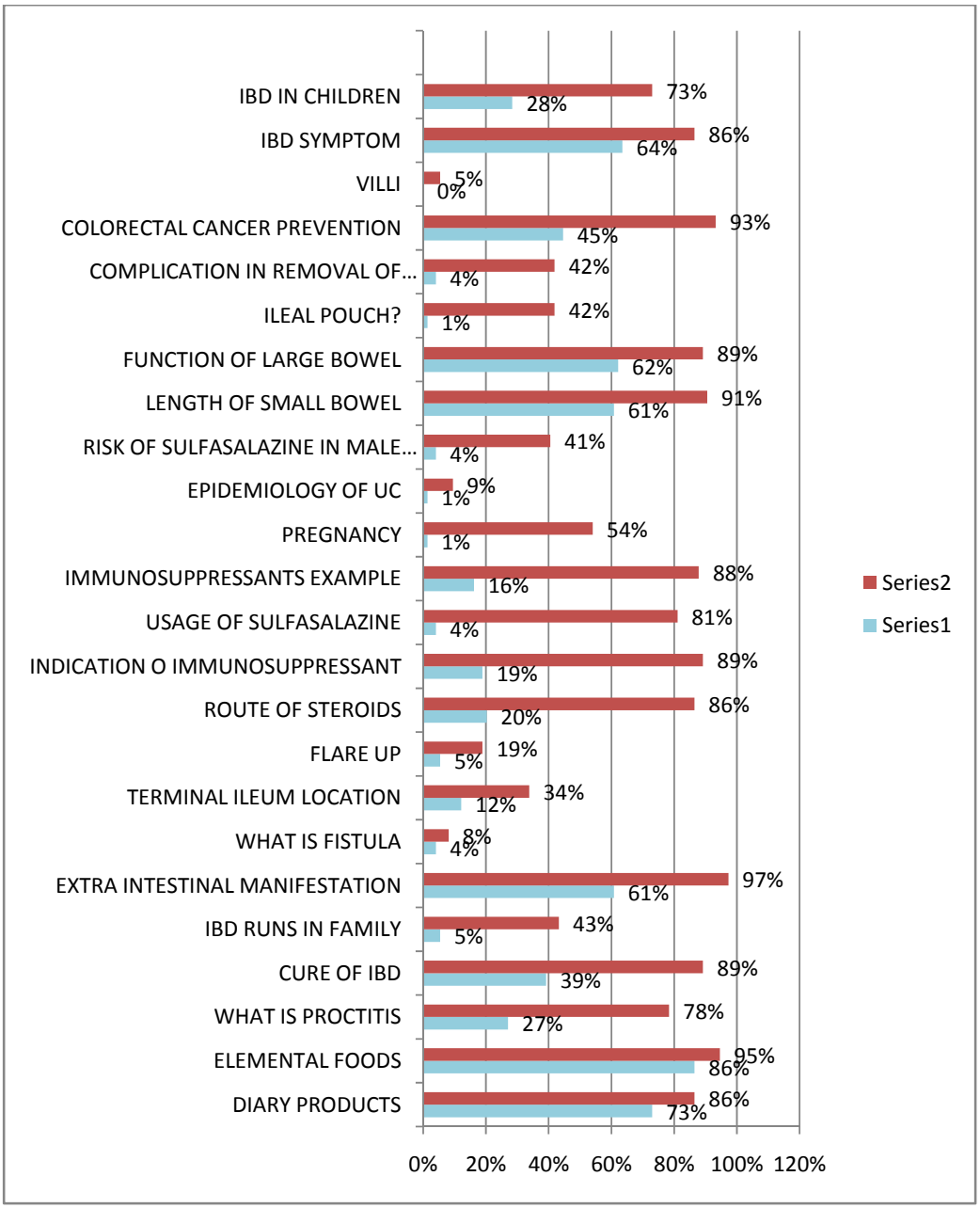


Fig.17: Percentage of correct answers for CCKNOW questionnaire before and after visit

Table 17: Demographic features and their association with patient knowledge (CCKNOW score)

Variable	No of patients	%	Mean± SD	p value
GENDER				0.2
Male	37	50%	2.97±0.49	
Female	37	50%		
AGE				0.18
20-40	34	45.9%	3.17±0.45	
41-60	28	37.8%	2.85±0.35	
61-80	12	16.2%	3.08±0.51	
EDUCATION STATUS				
Primary	34	45%	16.79±1.70	***0.01***
Secondary	30	40%	16.11±2.58	
Higher	10	13%	15.06±1.56	
EMPLOYEMENT STATUS				
Employed	29	39%	15.76±0.0123	0.06
Unemployed	31	41%	14.76±1.1232	
Student	14	18%	14.23±1.56	

Table 18: Demographic features and their association with patient knowledge (CCKNOW score)

Disease characteristics	No of patients N=74	Percentages	mean±SD	p value
Type of IBD				
UC	37	50%	16.63±1.64	
CD	37	50%	15.73±2.50	***0.04***
Duration of IBD(mnths)				
1-6	32	43.2%	16.25±1.70	
7-12	2	2.7%	14.50±2.12	0.09
>1 yr	27	36.5%	16.25±2.58	
IBD related surgeries				
Yes	35.1%	35.1%	3.2±0.42	0.1
No	64.9%	64.9%	2.91±0.40	
Intestinal manifestations				
Arthralgia	16	21.6%	3.12±0.50	
Bache ache	7	9.5%	3.14±0.69	0.11
Hepatobiliary	1	1.4%	2.00	
Skin lesion	1	1.4%	3.00	
Nil	49	66.2%		
Location				
UC Proctitis	12	16.2%	16.50±1.50	
Left colon	6	8.1%	17.83±1.32	
Pancolitis	16	21.6%	16.00±1.46	0.442
CD ileal	12	16.2%	15.91±1.97	
Ileocolonic	20	27.2%	15.75±2.48	
Colonic	8	10.8%	16.25±3.61	
IBD related hospitalization				
Yes	6	8.1%	16.50±2.07	
No	38	51.4%	16.23±2.12	0.09
>1	30	40.5%	16.25±2.58	

Table 19: COMPARSON OF SIBDQ SCORES OF IBD PATIENTS BEFORE AND AFTER INTERVENTION

Sl.No	Components	Before intervention Mean±SD	After intervention Mean±SD	Before-After Intervention p value
1	Feeling of fatigue	1.0135±0.1162	1.0000±.0000	.321
2	Cancellation of social engagement	5.3514±6.08711	6.1081±0.4844	.288
3	Difficulties in doing sports activities	4.6892±1.18120	6.0811±.46099	***0.02***
4	Paining in the abdomen	4.7568±1.20286	6.0946±.55317	***0.04***
5	Feeling depressed	4.8919±1.1173	6.0946±0.5531	***0.03***
6	Difficulties in passing gas	1.3919±0.4915	1.0270±0.1632	.000
7	Problems on getting weight	1.9595±.19857	1.9189±.27482	.260
8	Feeling relaxed	4.7027±1.22452	2.8514±.90179	***.000***
9	Feels to go to bathroom	4.8243±1.06447	6.2432±.67865	***.000***
10	Feeling angry	4.8919±1.11733	6.2432±.61512	***.000***
11	Total BDI score	46.9324±9.021	58.2703±3.0757	***.000***

Table 20: COMPARISON OF DOMAINS OF SIBDQ SCORES BEFORE AND AFTER INTERVENTION

Sl.No	Components	Before intervention	After intervention	p value
		Mean±SD	Mean±SD	
1	Systemic	9.5946±2.0062	12.3378±0.81555	.000
2	Social	9.3514±2.3433	12.1892±0.8707	.000
3	Bowel	14.3919±3.0512	18.5000±1.3059	.000
4	Emotional	14.4865±3.0576	15.2055±1.09238	.068

Table 21: COMPARISON OF DEMOGRAPHIC CHARACTERISTICS WITH SIBDQ DOMAINS

CHARACTERISTICS		n=74	SYSTEMIC		SOCIAL		BOWEL		EMOTIONAL	
			Mean±SD	p value	Mean±SD	p value	Mean±SD	p value	Mean±SD	p value
Gender	Male	37	12.32±0.93	.480	12.13±1.08	.597	18.56±1.51	.659	15.27±1.10	.527
	Female	37	12.405±0.68		12.24±0.59		18.43±0.9586		15.10±1.219	
Age	20-40	34	12.32 ± .87	.746	12.00±0.49	.228	18.32±1.47	.0569	15.38±1.1	.350
	41-60	28	12.28±0.76		12.35±1.19		18.64±1.22		15.07±1.083	
	61-80	12	12.50±0.79		12,33±0.77		18.68±0.98		14.91±1.09	
Educational status	Primary	13	12.21±0.85	.707	11.94±1.1772	.653	18.43±1.3	.761	15.42±.9015	.664
	Secondary	27	12.48±0.653		12.36±0.70		18.36±1.25		15.04±1.09	
	Higher	21	12.23±0.99		12.19±0.81		18.52±1.0		15.±1.060	
Past History	DM	11	12.00±0.447	.635	12.0±0.000	.495	18.90±0.83	.56	15.36±1.120	.727
	HT	3	12.33±0.5773		13.00±1.000		18.66±.57		15.66±0.57735	
	Intestinal Disorder	1								
	IBD	9	12.44±0.52		12.44±0.88		17.55±1.740		15.2±0.971	
	Other	11	12.18±1.40		12.00±0.89		17.90±1.77		14.72±1.79	
Surgery	Yes	26	12.42±0.71	.512	12.0±0.426	.393	18.41±1.24	.712	15.25±1.05	.124
	No	48	12.37±0.83		12.12±0.95		18.45±1.41		15.33 ±1.05	
Appendictitis	Yes	12	12.166±0.71	.04	12.00±.426	.415	18.41±1.24	.811	15.25±1.0	.835
	No	62	12.37±0.83		12.22±0.93		18.51±1.32		15.17±1.10	

Charecteristics	**n=74**	**Systemic**	**Social**	**Bowel**	**Emotional**					
		Mean ±SD	**p value**	**Mean±SD**	**p value**	**Mean ±SD**	**p value**	**Mean± SD**	**p value**	.
	Tea	22	12.63±0.65		12.40±0.734		18.77±0.8		15.13±0.88	.947
Food habits	Veg	12	12.50±0.52	.456	12.58±0.9	.087	18.50±1.24	.001	14.9167±1.08	
	Non veg	62	12.30±0.860		12.11±0.85		18.5000±1.3		15.24±1.09	.349
Family history	First relative Second relative Nil	22 1 51	12.09±0.61 13.00 12.33±0.81	.189	12.04±1.09	.082	18.50 ±1.40	.930	15.45±0.96	.0246
Psycho factors	Stress emotion	69 5	12.31±0.83 12.60±0.54	.460	12.20±0.90	.618	18.50±1.21	.217	15.15±1.10	.0388
Duration of IBD	1-6 mnths 7-12 mnths >1 yr nil	32 2 27 13	12.37±0.70 12.50±0.70 12.37±0.62 12.15±0.81	.843	12.37±0.70	.094	18.34±0.6	.871	13.45±1.0	.232

Table 22: MEAN AND STD DEVIATION OF PATIENT SATISFACTION SCORE

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
psq1	74	1.00	4.00	1.7027	.59056
psq2	74	1.00	4.00	2.3378	.60312
psq3	74	1.00	4.00	2.2568	.52501
psq4	74	4.00	5.00	4.3243	.47132
psq5	74	2.00	4.00	2.7162	.74980
psq6	74	1.00	4.00	2.2973	.71634
psq7	74	2.00	5.00	3.0405	.86704
psq8	74	1.00	5.00	3.5135	1.01013
psq9	74	1.00	2.00	1.2973	.46019
psq10	74	2.00	5.00	3.4595	.62349
psq11	74	2.00	5.00	2.6757	.68463
psq12	74	2.00	5.00	3.2027	.85975
psq13	74	2.00	4.00	3.2027	.79346
psq14	74	2.00	5.00	4.2973	.71634
psq15	74	2.00	5.00	3.3784	.80585
psq16	74	1.00	4.00	2.2432	.80768
psq17	74	2.00	5.00	3.8378	.57403
psq18	74	1.00	4.00	2.8378	.90701

RESULTS AND DISCUSSION

Inflammatory Bowel Disease is characterized as a chronic disorder that are related to unknown aetiology. Disease-related knowledge plays a critical role in facilitating patients' acceptance of their diagnosis and compliance with active participation in the treatment of inflammatory bowel disease (IBD). This prospective observational study was aimed to measure the deficits in knowledge and their quality of life

I. DEMOGRAPHIC FEATURES

A total of 74 patients were enrolled in the study. There were equal number of males and females,37 patients. The mean age of this study participants was 1.7027±.73521,

a) Age: Out of which 36 (48.6%) were UC patients and 38(51.4%) were CD patients. There were 34 patients falls within the age group 20-40(45.9%). The type of UC and CD distribution in this age group is equally 17(22.97%). And 28 patients falls within the age group 41-60(37.8%). The type of UC and CD distribution in this age group is 14(18.92%). There were 12 patients in the age group 61-80 and was 6.76% and 9.46% respectively. Our study correlates with the study conducted by **Reghu *et al***as the majority of their patients came under age group 20-40 years.
b) Gender: Gender wise distribution in this study was 37 male and 37 female patients. Out of 37 male patients 21(28.38%) were having UC and 16(21.62%) were having CD. The type of UC and CD distribution in the female category was 15(20.27%) and 22(29.73%) respectively. Same result was obtaines in a study conducted by **Sumant s arora** which reveals that the females were predominance in CD and males were predominance in UC.
c) Comorbid condition: In this study population (74),without any comorbidity condition were 39. The UC(20) and CD (19) distribution, 27.03% and 25.68% respectively. There were 9 IBD patients with 2 UC patients and 7 CD

patients,2.70% and 9.46% respectively. Among 35 UC patients 11(14.9%) patients were having DM and only 3(4.1%) were having HT.

d) Appendicitis: In this study there were only 12(16.2%) patients having appendictitis and were equally having UC and CD. But some of the studies shows that appendectomy increased the risk of IBD. But 62 patients were not having appendicitis. In the study conducted by **Ana Catarina*et al*** result shows that appendectomy seems positively associated with the development of Crohns disease, so appendectomy should be avoided inorder to avoid the worsening the prognosis of IBD.

e) Epidemiological study: Epidemiological studies have provided compelling evidence that genetic factors contribute to the pathogenesis of IBD. First degree relatives of patients with IBD have approximately a 3 to 20 fold greater likelihood of developing the general population. So in this study,23,(29% of total population) patients were having their relatives with IBD diagnosis. In this study relatives of CD patients having moe than that of UC. The same result was obtained by a study conducted by **David kevans** there was FDR of CD patients having IBD than UC patients.

f) Psychological factors: On analyzing the psychological factors like stress, emotion on IBD patients, patients with stress were the most than emotion. distribution of stress factor in 33 UC patient 44.59% and 48.65%. This resembles the study conducted by **Jorgensen** et al reported that these worries and stress can be regarded as a normal feature of life and cannot be related with the risk of developing the disease.

g) Life style habits: Based on the lifestyle of the patients,most of them were taking coffee(68.9%) and 29% of patients were taking tea and most of the patients 62(83.8%) were non vegetarians and only 12(16.2%) were vegetarians.

II. DISEASE CHARACTERISTICS

a) Extra intestinal manifestation: In this study extra intestinal manifestations were grouped into 5 categories. There were 16 patients having arthralgia, among that patients with UC is 9(9.46%), 7 patients having bache ache and there were only one patient having hepatobiliary and skin lesion.

b) Disease severity: The disease severity was classified into 3 categories, mild, moderate and severe. Patients who diagnosedas mild condition in 11 patients and 21 CD patients respectively. In UC, there were 19 patients (25.68%) were in moderate condition and 15 (20.27%) in CD. Only 8 patients were in severe condition .

c) Localisation of the disease: The localization of the disease were classified into 4 categories in both UC and CD. The four groups in UC were proctitis, left colon, pan colitis and small intestine alone and in CD the groups were proximal, ileal, ileocolonic and colonic. Anyway 12 UC patients (16.22%) were having proctitis, 6 (8.11) were having left colonic inflammation. In 16 CD patients (22%)pancolitis 12 (16.22%)ileal 20(27.88%) ileocolonic 8 (11.5%)colonic inflammation.

d) Relapse the condition: There is more chance of re occurring the disease again in some patients. Some of the studies shows so. In this study only 11 patients were relapsed one.(15.6%).

CCKNOW

The mean CCKNOW score during the baseline visit and the revisit period were 6.56±3.26 and 16.17±2.16 respectively. The mean CCKNOW scores were statistically significant during revisit from baseline visit(p value .000). According to the questions, during the baseline visit the percentage of IBD knowledge varies from 0% to 86 % and only less than 50% with correct answers for 18 out of 24 questions. The knowledge level was reassessed in the revisiting time and it ranged from 5% to 97%, among all the questions only 9 questions got less than 50% of correct answers. Among the questions, the question on elemental food showed higher percentage of

correct answer in the baseline visit 86% and in revisit it showed 95% in revisit. The question on extra intestinal manifestation shows higher percentage of correct answer. The question on villi showed least percentage of correct answer in baseline visit and it showed only 5% in revisit.

In this study, we have compared demographic characteristic and the CCKNOW score. The results showed that, male patients have the mean CCKNOW score of 1.72±0.69 and female patient with the score of 1.67±0.78. This shows Male patients had higher mean CCKNOW score than females patients which was statistically significant(p=0.039).

Younger age of diagnosis was associated with higher mean CCKNOW scores.ie the age group 20-40years had higher mean CCKNOW score (16.79±1.70) compared to the age group 41-60 years(15.5±2.30) and 61-80years(16.0±2.16) with the statistical analysis of (p<0.28). This is a similar result from the study conducted **Jason k How*et al***.

Secondary educated patients having higher mean score 16.11±2.58 than higher educated 15.06±1.56 and primary 16.01±0.09 educated patients showed statistically significant.(p>0.01). Employed patients there was higher mean score 15.76±0.0123 than unemployed 14.76±1.1232 and students 14.23±1.56,(p>0.06**). C.P Sellinger *et al*** studied out that the patients with higher education shows good knowledge score.

Patients with ulcerative colitis(UC) had higher CCKNOW score 16.63±1.64 compared to patient with crohns disease 15.73±2.50,(p>0.004). Duration of IBD were grouped into 4 sub division, in which period of >1yr had the higher mean score of 16.25±1.70. However extra intestinal manifestation, family history, IBD related hospitalization were not significantly associated with CCKNOW score. **But Yang Sook Yoo** observed that CD patients were having more score than UC patients.

SIBDQ

Comparison of SIBDQ components

The SIBDQ, consisting of totally 10 questions which examines four domains: bowel symptoms, systemic, emotional and social functions. The comparison of quality of life was done before and after intervension of the patients. Each component shown the difference in the mean value. The components got significant difference in systemic domain, social domain, and in bowel domain.($p<0.05$). In our study, females were found to be more mean score than males in every the domain.

Association of SIBDQ with Demograhic Characters

The importance of HRQOL in chronic diseases has been increasingly reliable because of its implication on patients psychological well being and social adjustment to the illness. Measuring HRQoL provides important data to quantify the impact of the disease on the daily life of patients. The association between different domains of SIBDQ with demographic charecters wereanalysed and it was observed that age and past history had that significant relation with bowel domain($p<0.05$). Also the patients with comorbid condition had better QoL in bowel domain(<0.05). In a study conducted by **Azza A** E ***et al*** it was reported that relapse, long duration(>5yrs), low education and young age at disease onset may increase the risk of patients with decreased HRQOL.

Comparison of CCKNOW with SIBDQ

In this study,knowledge scores were compared with QoL scores before and after the intervention of patient. It is found that the mean score of knowledge was increased from the baseline visit. The mean score of the QoL is also increased from base line visit. But significantly both CCKNOW and SIBDQ has no relation.

Significance between scores of before intervension of knowledge and qol is found to be (<0.09) and after intervention it is found to be(<0.324). **How JK *et al*** also

done a same study on this topic and found out that the patient knowledge was not having any correlation with the quality of life of IBD patients.

Patient Satisfaction

On patients revisit, they were provided with a satisfaction form inorder to get the feed back of the patients regarding PSQ-18 were used and each question pointed by 5 point likert scale. The mean score was found to be 2.94 which can be regarded as the patients are neither satisfied nor unsatisfied.

CONCLUSION

Disease related knowledge plays a vital role in facilitating patient's acceptance of their diagnosis and compliance with active participation in the treatment of inflammatory bowel disease (IBD). In this study it was observed that disease related knowledge was less during the baseline visit without regular follow up of the patient.The result shown slight improvement in patient knowledge with the post test and proper follow up was noted in patient with patient information leaflet in the re visit. From the study it proves that patient education programme is essential for better understandingabout the disease and their management in quality of life. This study revealed,there is no more relationship between knowledge assessment and quality of life in IBD patients.

LIMITATION OF THE STUDY

The main limitation of this study is duration and follow up of the patient. As IBD incidence and prevalence is less and awareness about the disease is rare, population enrolment is minimal with short span of time and to have the medication adherence, long term follow up of study is mandatory. Only very few studies have performed by clinical pharmacist in this disease. In future we planned to study the patient comprehensively from enrolment to discharge and to fill the gap identified in the patient by overcoming knowledge deficit regarding IBD.

REFERENCES

1. Yi-Zhen Zhang, Yong-Yu Li.Inflammatory bowel disease: Pathogenesis . World J Gastroenterol 2014 January 7; 20(1): 91-99
2. Atsushi Nishida, Ryo Inoue, Osamu Inatomi ,Shigeki Bamba ,Yuji Naito ,Akira Andoh. Gut microbiota in the pathogenesis of inflammatory bowel disease. Clinical Journal of Gastroenterology (2018) 11:1–10
3. Duk Hwan Kim , Jae Hee Cheon. Pathogenesis of Inflammatory Bowel Disease and RecentAdvances in Biologic Therapies. Immune network 2017.17.1.25
4. Seung Hoon Lee, Jeong eun Kwon, Mi-La Cho. Immunological pathogenesis of inflammatory bowel disease. 2018;16(1):26-42.
5. Subasinghe D, Wijekoon N S, Nawarathne N M M, Samarasekera D N. Disease-related knowledge in inflammatory bowel disease: experience of a tertiary care centre in a developingcountry in South Asia. Singapore Med J 2010; 51(6) : 484.
6. Yang-Sook Yoo , Ok-Hee Cho , Kyeong-Sook Cha . Disease-Related Knowledge andInformation Needs Among Inflammatory Bowel Disease Patients in Korea. Gastroenterology Nursing 2015;38(6):455-463.
7. Saurabh Kedia Vineet Ahuja. Epidemiology of Inflammatory Bowel Disease in India: The Great Shift East. 2017;2:102–115.
8. Charles N. Bernstein, M.D, Andre Wajda, M.S. Lawrence W. Svenson, B.Sc. Adrian MacKenzie, B.Sc. Mieke Koehoorn, Ph.D. Maureen Jackson, M.Sc. Richard Fedorak, M.D. David Israel, M.D. and James F. Blanchard, M.D., Ph.D. The Epidemiology of Inflammatory Bowel Disease in Canada: A Population-Based Study Am J Gastroenterol 2006;101:1559–1568.
9. Sadiqul Islam, Mayank Agarwal, Anjam J Talukdar, Sangitanjan Dutt, Partha P Kalita. A study on clinical profileof patients with Inflammatory Bowel Disease . NJMR 2016 July-Sept:6(3):233-236.
10. Bani Ahluwalia, Luiza Moraes, Maria K. Magnusson & Lena Öhman. Immunopathogenesis of inflammatory bowel disease and mechanisms of biological therapies. Scandinavian Journal of Gastroenterology 53:4, 379-389.

11. Clara Abraham, M.D., and Judy H. Cho, M.D. Inflammatory Bowel Disease. N Engl J Med 2009;361:2066-78.
12. Judy H. Cho* and Steven R. Brant . Recent Insights Into the Genetics of Inflammatory Bowel Disease. Gastroenterology. 2011 May ; 140(6): 1704–1712.
13. Jannie Pedersen, Mehmet Coskun, Christoffer Soendergaard, Mohammad Salem, Ole Haagen Nielsen. Inflammatory pathways of importance for management of inflammatory bowel disease. World J Gastroenterol2014 January 7; 20(1): 64-77.
14. Subasinghe D, Wijekoon N S, Nawarathne N M M, Samarasekera D N. Disease-related knowledge in inflammatory bowel disease: experience of a tertiary care centre in a developing country in South Asia.Singapore Med J 2010; 51(6) : 484-489
15. Richard A. Wardle and John F. Mayberry. Patient knowledge in inflammatory bowel disease:the Crohn's and Colitis Knowledge Score Eur J Gastroenterol Hepatol 26:1–5.
16. Julián Panésa, , Marian O'Connor b, Laurent Peyrin-Biroulet c, Peter Irving d,
17. Joel Petersson e, Jean-Frédéric Colombel. Improving quality of care in inflammatorybowel disease: What changes can be made today?. Journal of Crohn's and Colitis (2014) 8, 919–926.
18. Giorgos Chouliaras, Daphne Margoni, Konstantina Dimakou, Smaragdi Fessatou, Ioanna Panayiotou, Eleftheria Roma-Giannikou. Disease impact on the quality of life of children withinflammatory bowel disease. World J Gastroenterol2017 February 14; 23(6): 1067-1075.
19. Jason K Hou, Joshua A Turkeltaub, Thomas R McCarty III, Hashem B El-Serag. Assessment of disease specific knowledge and health-related quality of life among United States military veterans with inflammatory bowel disease. World J Gastroenterol 2015 May 21; 21(19): 6001-6007.
20. Anisah Soobraty, Sarah Boughdady. Current practice and clinicians perception of medication non adherence in patients with inflammatory bowel disease. World J Gastrointest Pharmacol Ther 2017 February 6;8(1):67-73.

21. Karthika Ashok, Anju. A Mathew, Anjana Thomas, Devika Mohan, Rajesh Gopalakrishna, Remya Reghu1. Clinical Pharmacist's Interventions on Medication Adherence and Knowledge of Inflammatory Bowel Disease Patients. J Young Pharm, 2017; 9(3):381-385.
22. Guo-Bo Chen, Sang Hong Lee, Grant W. Montgomer, Naomi R. Wray, Peter M. Vissche. ,Performance of risk prediction for inflammatory bowel disease based on genotyping platform and genomic risk score method. BMC Medical Genetics (2017) 18:94.
23. Gabriella Velonias, BS1, Grace Conway, BS1, Elizabeth Andrews, BS1, John J Garber, MD Hamed Khalili, Vijay Yajnik, MD PhD and Ashwin N Ananthakrishnan . Older age and health-related quality of life in inflammatory bowel diseases. Inflamm Bowel Dis. 2017 February ; 23(2): 283–288.
24. Dibley L, Bager P, Czuber-Dochan W, Farrell D, Jelsness-Jørgensen LP, Kemp K, Norton C. Identification of Research Priorities for Inflammatory Bowel Disease Nursing in Europe: a Nurses-European Crohn's and Colitis Organisation Delphi Survey. J Crohns Colitis. 2017 Mar 1;11(3):353-359.
25. Ana Catarina Caetano Fonseca Loureiroa,∗, Laura Elisabete Ribeiro Barbosa. Appendectomy and Crohn's Disease Ana Catarina. J Coloproctol (Rio J). 2018.
26. Wheat CL*, Megan Maass, Beth Devine, Timothy Thornton, David Grembowski and Cynthia W Ko. Wheat, Educational Needs of Patients with Inflammatory Bowel Disease (IBD) and Non-Adherence to Medical Therapy-A Qualitative Study.., J Inflam Bowel Dis & Disord 2016,1:1.
27. Azza. A. E. Mahalli, H.M. Ali Alharthi. Asssessment of health related quality of life of patients with inflammatory bowel diseases in Eastern provinence, Saudi Arabia. Journal of infection and public health (2017),10,93-101.
28. Sasha Taleban,Kathleen O. Stewart Darrick K. LiPrashant SinghDarrell S. PardiHolly C. SturgeoClinical Activity and Quality of Life Indices Are Valid Across Ulcerative Colitis But Not Crohn's Disease Phenotypes Dig Dis Sci (2016) 61:2627–2635.
29. Anilga Moradkhani a, , Linda J. Beckman a, James H. Tabibian Health-related quality of life in inflammatory bowel disease: Psychosocial, clinical,

socioeconomic, and demographic predictors. Journal of Crohn's and Colitis (2013) 7, 467–473.

30. Hyuk Yoon1, Suk-Kyun Yang, Hoonsub So, Ko Eun Lee, Sang Hyoung Park, Sung-Ae Jung3, Joong Haeng Choh, Cheol Min Shin, Young Soo Par1, Nayoung Kim, and Dong Ho Lee . Development, validation, and application of a novel tool to measure disease-related knowledge in patients with inflammatory bowel disease .The Korean Journal of Internal Medicine. 2017 Nov 29.
31. J. Burisch , P. Weimersa, N. Pedersen , S. Cukovic-Cavka , B. Vucelic ,J. Burisch , P. Weimersa, N. Pedersen, S. Cukovic-Cavka, Vucelic Health-related quality of life improves during one year of medical and surgical treatment ina European population-based inceptioncohort of patients with Inflammatory Bowel Disease a European population-based inception cohort of patients with Inflammatory Bowel Disease An ECCO-EpiCom study.Journal of Crohn's and Colitis (2014) 8, 1030–1042
32. Gert Huppertz-Hauss, MD, Marte Lie Høivik, PhD, Ebbe Langholz, PhD, Selwyn Odes, PhD,Milada Småstuen, PhD,k Reinhold Stock brugger, PhD,Geir Hoff, PhD, Bjørn Moum, PhD, and Tomm Bernklev, PhD .Health-related Quality of Life in Inflammatory Bowel Disease ina European-wide Population-based Cohort 10 Years After Diagnosis. Inflamm Bowel Dis 2015;21:337–344)
33. Joana Magahaese, Francisca Dias de casrtro1, Pedro Boal caeveol, Sílvia leitei Maria João Moreria and José cotter,.Quality of life of patients with inflammatory bowel disease importance of clinical, demographic and psychosocial factors. v. 51 no. 3 - jul./set. 2014.
34. Irina Blumenstein a, Edel McDermott b, Denise Keegan b, Kathryn Byrne b, Martha Ellison, Glen Doherty b, Oliver Schröder a, Hugh Mulcahy b,Sources of information and factual knowledge in Europeans with inflammatory bowel diseases:A cross-cultural comparison between German and Irish patients Journal of Crohn's and Colitis (2013) 7, e331–e336.
35. Amitha Prasad Gumidyala, MS, and Rachel Neff Greenley, phd, Correlates of Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease: A

Cumulative Risk Model Approach Journal of Pediatric Psychology 39(1) pp. 55–64, 2014.

36. Lars-Petter Jelsness-Jørgensen, BjørnMoum, and Tomm Bernklev. Worries and Concerns among Inflammatory Bowel Disease Patients Followed Prospectively over One Year.Gastroenterology Research and Practice Volume 2011, Article ID 492034, 8 pages.
37. Christian P. Selinger Simon Lal , Jayne Eaden , D. Brian Jones, Peter Katelaris, Grace Chapman , Charles McDonald ,Rupert W.L. Leong , John McLaughlin. Better disease specific patient knowledge is associated with greater anxiety in inflammatory bowel disease.Journal of Crohn's and Colitis (2013) 7, e214–e218.
38. Laurie Keefer, Jennifer L. Kiebles, and Tiffany H. Taft. The Role of Self-Efficacy in Inflammatory Bowel Disease Management: Preliminary Validation of a Disease-Specific Measure.Inflamm Bowel Dis. 2011 February ; 17(2): 614–620.
39. Fabiana Castiglione, Maria Diaferia , Fabrizio Morace , Orazio Labianca, Costantino Meucci Antonio Cuomo , Antonio Panarese , Marco Romano ,Italo Sorrentini , Caterina D'Onofrioa, Nicola Caporaso , Antonio Rispo.Journal of Crohn's and Colitis (2012) 6, 324–329.
40. Subasinghe D, Wijekoon N S, Nawarathne N M M, Samarasekera D N.Disease-related knowledge in inflammatory bowel disease: experience of a tertiary care centre in a developing country in South Asia.Singapore Med J 2010; 51(6) : 484.
41. Antonina A Mikocka-Walus Deborah A Turnbull, Nicole T Moulding,Ian G Wilson, Gerald J Holtmann and Jane M Andrews. Does psychological status influence clinical outcomes in patients with inflammatory bowel disease (IBD) and other chronic gastroenterological diseases: An observational cohort prospective study.BioPsychoSocial Medicine 2008, 2:11.
42. Barbara M Waters RN(EP) MN, Louise Jensen RN PhD, Richard N Fedorak MD.Effects of formal education for patients with inflammatory bowel disease: A randomized controlled trial.Can J Gastroenterol Vol 19 No 4 April 2005.

43. Carol S Burckhardt and Kathryn L Anderson. The Quality of Life Scale (QOLS): Reliability, Validity, and Utilization.Bio med central Health and Quality of Life Outcomes 2003, 1:60
44. Giorgos Bamias, MD; Mark R. Nyce, MD; Sarah A. De La Rue, PhD; and Fabio Cominelli, MD, PhD.New Concepts in the Pathophysiology of Inflammatory Bowel Disease . Ann Intern Med. 2005;143:895-904.
45. M J Carter, A J Lobo, S P L Travis, on behalf of the IBD Section of the British Society ofGastroenterology..ut 2004;53(Suppl V):v1–v16.
46. David Kevans, Mark S. Silverberg, Krzysztof Borowski,a Anne Griffiths, Wei Xu, Venus Onay, Andrew D. Paterson, Jo Knightf, Ken Croitoru;a, on behalf of the GEM Project. IBD Genetic Risk Profile in Healthy First-Degree Relatives of Crohn's Disease Patients Journal of Crohn's and Colitis, 2016, 209–215.
47. Michael D. Kappelman, Millie D. Long, Christopher Martin1, Darren A. DeWalt1, Patricia M. Kinneer1, Wenli Chen1, James D. Lewis2, and Robert S. SandlerUniversity .Evaluation of the Patient Reported Outcomes Measurement Information System in a large cohort of patients with Inflammatory Bowel Diseases.Clin Gastroenterol Hepatol. 2014 August ; 12(8): 1315–23.e2.
48. Sanna Lonnfors, Severine Vermeire, Marco Greco, Daan Hommes. IBD and health related quality of life- Discovering true Impact . Journal Of Cronhs and Colitis (2014)8 1281-1286.
49. Allison R. Wilcox, MD, Maria Concepcion C. Dragnev, APRN, Christopher J. Darcey, MD, and Corey A. Siegel, MD, MS. A New Tool to Measure the Burden of Crohn's Disease and Its Treatment: Do Patient and Physician Perceptions Match? Inflamm Bowel Dis. 2010 April ; 16(4): 645–650.

Self Help – What can you Do?

- High calorie, high protein diet.
- Try to have on food at right time.
- Take vitamin and mineral supplements.
- Take foods in regular interval and avoid large meals at a time

Don't s

- Avoid dairy products
- Avoid caffeine
- Avoid carbonated drinks (beer ,wine, alcohol)
- Avoid mayonnaise , margarine
- Avoid nuts and seeds.
- Avoid junk foods and spicy foods
- Don't take ibuprofen and paracetamol

For more Information Contact:

Dr. S. ARAVINDH.MD.DM
Consultant Gastroenterologist
KMCH Hospital
(OR)
Department of Pharmacy Practice
KMCH College of Pharmacy,
Phone: 04224323414

KOVAI MEDICAL CENTER & HOSPITAL

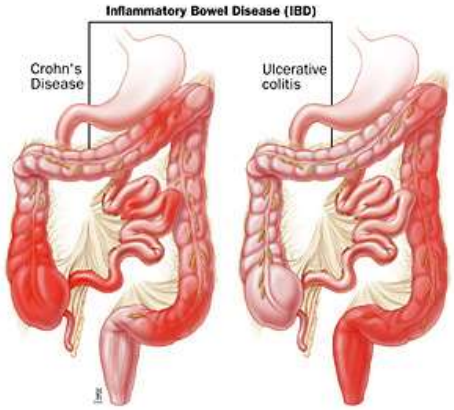
INFLAMMATORY BOWEL DISEASE

What is inflammatory bowel disease?

Inflammation of various regions in the GI tract.

Its of two types

- ULCERATIVE COLITIS (UC)
  It affects the entire large intestine, begins in rectum and moves upward.
- CROHN'S DISEASE (CD)
  It affects any part from mouth to anus.



CAUSES:

- Genetics

- Environmental factors

Family history  Stress

Emotions 

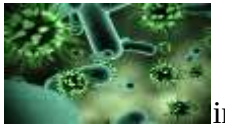
SIGNS AND SYMPTOMS:

Diarrhoea

Constipation

Abdominal pain

fever



infection

Complications of IBD

- Mouth ulcers
- Uveitis
- Renal stones
- Arthritis

How to manage IBD?

a. Follow a low residue diet to relieve abdominal pain and diarrhea.
b. Try to follow this treatment plan as closely as possible
c. Limit dairy products
d. Try low-fat foods
e. Take care with fiber
f. quitting smoking
g. avoid stress
h. Mild exercise can help reduce stress, relieve depression and normalize bowel function.
i. Regular relaxation and breathing exercises

DATA COLLECTION FORM

IP/ OP. No: **DATE:**

NAME: **AGE/SEX:**

WEIGHT: **HEIGHT:**

PRESENT COMPLAINTS:

PAST MEDICAL HISTORY:

PREVIOUS HISTORY OF SURGERY: YES ☐ NO ☐

APPENDICTITIS: YES ☐ NO ☐

LIFE STYLE HABITS: Coffee ☐ Tea ☐ Smoking ☐ Alcohol ☐

FOOD HABITS: VEG ☐ NON-VEG ☐

- Fibrous
- Non – Fibrous
- Traditional Food
- Junk Food

OCCUPATION:

FAMILY HISTORY:

FIRST RELATIVE ☐ SECOND RELATIVE ☐ NIL ☐

PSYCHOLOGICAL FACTORS: STRESS ☐ EMOTION ☐ TRAUMA ☐

NEWLY DIAGNOSED: YES ☐ NO ☐

TYPE OF IBD: UC ☐ **CD** ☐

DURATION OF IBD (months): 1-5 ☐ 6-10 ☐ >1yr ☐

IBD RELATED HOSPITALIZATION: Nil ☐ >1 ☐

CLINICAL FEATURES:

ABDOMINAL PAIN		CONSTIPATION	
MUCUS IN STOOLS		PERI ANAL DISEASE	
FEVER		ANO RECTAL PAIN	
BLOOD IN STOOLS		ANAL FISSURE	
RECTAL URGENCY		PERI ANAL FISTUAL	
CHRONIC DIARRHOEA		PEDAL EDEMA	
PALLOR		ABDOMINAL MASS	
WEIGHT LOOSE		MOUTH ULCER	

EXTRA INTESTINAL MANIFESTATIONS:

Type of manifestation

Arthralgia		Backache		Skin lesion		Ocular		hepatobilary	

LAB INVEATIGATION

DATE			
TC			
ESR			
ALBUMIN			
CRP			
Hb			

INVESTIGATION

COLONOSCOPY	
RETROGRADE ILEOSCOPY	
OGD	
ABDOMINAL CT	
BIOPSY	
USG	

DISEASE SEVERITY: MILD ☐ MODERATE: ☐ SEVERE: ☐

LOCALISATION OF DISEASE:

UC: Proctitis ☐ Left colon ☐ Pan-colitis ☐ NA ☐

CD: Proximal ☐ Ileal ☐ Ileo-colonic ☐ Colonic ☐

IBD RELAPSED PATIENT: YES ☐ NO ☐

COMPLICATION:

MANAGEMENT:

DRUGS	DOSE	FREQ	INDICATION	MODE OF ADMINISTRATION	V_1	V_2	V_3
Mesalamine							
Sulfasalazine							
Steroids							
Azathioprine							
Biologicals							
TPN							
Blood Transfusion							
Surgery							

Diet (2 questions)

Q1. Patients are allowed to eat dairy products

Q2. Elemental feeds are very easy to digest.

General IBD knowledge (11 questions)

Q3. Proctitis is a form of colitis that affects the rectum or back passage only.

Q4. Being symptom-free for three years does not mean IBD is cured.

Q5. IBD runs in families.

Q6. Inflammation can occur in other parts of the body as well as the bowel.

Q7. A fistula is an abnormal track between two pieces of bowel or between the bowel and skin.

Q8. The terminal ileum is a section of the bowel just before the anus

Q9. During a flare-up of IBD, the platelet count in the blood rises

Treatments (5 questions)

Q10. Steroids can be given in the form of an enema into the back passage.

Q11. Immunosuppressive drugs are given to IBD patients to reduce inflammation in the bowel.

Q12. Sulfasalazine is used to reduce the frequency of flare-ups.

Q13. Azathioprine is an immunosuppresive drug.

Q14. A woman with Crohn's disease may find it more difficult to become pregnant.

Q15. Ulcerative colitis is common in Europeans and North Americans.

Q16. Male patients who take sulfasalazine have reduced fertility levels that are reversible.

Q17. The length of the small bowel is approximately 6 m.

Q18. The function of the large bowel is to absorb water.

Q19. Another name for an ileorectal anastomosis operation with formation of a reservoir is pouch.

Q20. If terminal ileum is removed during surgery, the patient will have impaired absorption of vitamin B12.

Q21. Patients with IBD which has lasted for 8–10 years need to be screened .for cancer of the colon.

Q22. There are millions of tiny "hairs" in the small bowel to increase the absorptive surface, which are called villi.

Q23. Headache is not a common symptom of IBD.

Q24. A child who has IBD probably will not be as tall as his or her friends.

THE PATIENT SATISFACTION QUESTIONNAIRE SHORT-FORM (PSQ-18)

Grant N. Marshall and Ron D. Hays

P-7865

Published 1994 by RAND
1700 Main Street, P.O. Box 2138, Santa Monica, CA 90407-2138
To order RAND documents or to obtain additional information, contact Distribution Services: Telephone: (310) 451-7002; Fax: (310) 451-6915; Internet: order@rand.org.

The Patient Satisfaction Questionnaire Short-Form (PSQ-18)

Grant N. Marshall and Ron D. Hays

RAND

Santa Monica, CA

P-7865

Abstract

This article reports on the development and psychometric properties of a short-form version of the 50-item Patient Satisfaction Questionnaire III (PSQ-III). The short-form instrument, the PSQ-18, contains 18 items tapping each of the seven dimensions of satisfaction with medical care measured by the PSQ-III: general satisfaction, technical quality, interpersonal manner, communication, financial aspects, time spent with doctor, and accessibility and convenience. PSQ-18 subscale scores are substantially correlated with their full-scale counterparts and possess generally adequate internal consistency reliability. Moreover, both the magnitude of the correlation coefficients and the overall pattern of correlations among PSQ-18 subscales are highly similar to those observed for the PSQ-III. These preliminary analyses support the use of the PSQ-18 in situations where the need for brevity precludes administration of the full-length PSQ-III.

The Patient Satisfaction Questionnaire Short-Form (PSQ-18)

Patient satisfaction has emerged as a critical outcome of medical care due to increasing emphasis on patients as consumers of services in the medical marketplace (Davies & Ware, 1988). The extent to which different delivery systems satisfy their patients is a major determinant of viability in this highly competitive environment. Patient satisfaction has been associated with patient adherence to medical recommendations (Korsch, Gozzi, & Francis, 1968; Sherbourne, Hays, Ordway, Dimatteo, & Kravitz, 1992), willingness to initiate malpractice litigation (Vaccarino, 1977), doctor shopping (Marquis, Davies, & Ware, 1983), and disenrollment from prepaid health plans (Ware & Davies, 1983).

Recognizing the importance of patient satisfaction in assessing quality of medical care, Ware and his colleagues developed the Patient Satisfaction Questionnaire (PSQ; Ware, Snyder, & Wright, 1976a, b). The initial measure consisted of 80 items and was intended to be applicable in general population studies and to be useful for planning, administration, and evaluation of health services delivery programs (Ware, Snyder, Wright, & Davies, 1983). In subsequent years, revisions of the instrument have been fielded in the RAND Health Insurance Experiment (Davies, Ware, Brook, Peterson, & Newhouse, 1986), the RAND Medical Outcomes Study (Marshall, Hays, Sherbourne & Wells, 1993), and various national surveys (Andersen, & Fleming, 1980; Aday, Fleming, & Andersen, 1984).

The most recent version of the instrument, the PSQ-III, consists of 50 items tapping global satisfaction with medical care as well as satisfaction with six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor and accessibility of care. The

PSQ-III contains several improvements over earlier versions. Recent research attests to the desirable psychometric properties of PSQ-III, and provides support for a hierarchical conceptualization of satisfaction with medical care (Marshall et al., 1993). Within this framework, satisfaction with care can be simultaneously represented as both an overarching general domain and a set of dimensions tapping unique aspects of satisfaction.

Despite the noteworthy characteristics of the PSQ-III, its 50-item length places significant burden on respondents, requiring approximately 10-15 minutes to complete. Development of an abbreviated, yet reliable and valid, version of the PSQ would increase the ease with which patient satisfaction could be measured and encourage its assessment for monitoring the delivery of medical care. The aim of the current research was to develop and assess the adequacy of a short-form version of the PSQ. In developing the short-form, a multiple-step strategy was adopted. First, using the full PSQ subscales as criteria, empirical and conceptual considerations were taken into account in selecting a set of items to comprise a short-form scale. Second, the dimensional structure of the short-form, the PSQ-18, was compared to that of the long-form. Third, the associations of the PSQ-18 scales with the corresponding long-form scales was assessed.

Method

Study Design and Sampling

The MOS, a four-year prospective study, was designed to examine the influence of specific characteristics of providers, patients, and health systems on outcomes of care. Detailed information on sampling strategies employed in the MOS has been described elsewhere (Rogers et al., 1992; Tarlov et al., 1989). Briefly, data were obtained from patients visiting physicians (general internists, family physicians, cardiologists, endocrinologists, diabetologists,

psychiatrists), psychologists, and other mental health providers practicing within three systems of care (health maintenance organizations, large multispecialty groups and solo practices) in three cities (Boston, Chicago, and Los Angeles).[1]

The MOS includes both a cross-sectional and a longitudinal component. For the cross-sectional component, patients were sampled from among literate English-speaking adults visiting participating practices during 9-day (on average) screening periods in 1986. Complete questionnaires were obtained for 74% of eligible patients in group practices (i.e., HMO and multispecialty groups) and 65% of patients in single specialty solo or small group practices (N = 22,462). A telephone interview was conducted with 5,341 patients to collect additional information and to ask them to enroll in the longitudinal panel. Ninety-one percent (N = 4,824) of interviewed patients agreed to enroll in the longitudinal study. Of these, a subset of 2,546 patients was selected. The MOS longitudinal panel consisted of adult (ages 18 and over) English-speaking patients who agreed to enroll in the study, completed a screening questionnaire, and suffered from one or more of four conditions: diabetes (N = 495), hypertension (N = 1311), heart disease (N = 303), and symtoms of depression (N = 886). Patients who enrolled in the MOS were better educated than those who did not enroll (Rogers et al., 1992).

[1]Physicians were sampled from lists obtained from the HMOs and national professional associations; only those who were board-certified and between the ages of 31 and 55 were eligible. The final sample of practitioners for this analysis included 362 medical specialty providers (194 internists, 91 family practice physicians, 40 cardiologists, 24 endocrinologists, 13 nurse practitioners) and 161 mental health specialty providers (76 psychiatrists, 74 psychologists, 11 master-level mental health providers).

Subjects

Patients for whom complete MOS baseline data were available for all analytic variables (N = 2,197) were included in these analyses. With respect to demographic characteristics, study participants averaged 55.83 years of age (SD = 16.21); 40% were male; 57% were married. Eighty percent were White, 14% were Black, 3% were Hispanic, 1% were Asian or Pacific Islander, and 2% were from other ethnic groups.

Measures

The PSQ-III was mailed to study participants approximately three months following their office visit in which they were screened for the study.

Patient satisfaction with medical care. The PSQ-III (see Appendix C) consists of 50 items[2] tapping seven aspects of satisfaction with care: general satisfaction (6 items), technical quality (10 items), interpersonal manner (7 items), communication (5 items), financial aspects (8 items), time spent with doctor (2 items), and accessibility and convenience (12 items). To control for acquiescent responding (Ware, 1978), the instrument contains both positively-worded and negatively-worded items. Participants were asked to indicate how they feel about the medical care they receive in general, with no reference to a specific time frame or visit. Responses to each item are given on a 5-point scale ranging from strongly agree to strongly disagree.

[2] An additional item is included among the PSQ-III items. This item, number 30, does not measure satisfaction with care and is not included in scoring.

Development of the Short-Form

Items were selected for inclusion in the short-form version on the basis of their association with long-form scale scores, subject to the restriction that each subscale be composed of an equal number of positively- and negatively-worded items. Item-scale correlations were generated using the Multitrait Analysis Program (Hays & Hayashi, 1990). Correlations were adjusted downward as necessary to correct for inflation caused by item-scale auto correlation. Internal consistency reliability estimates for the PSQ-18 scales were calculated using Cronbach's (1951) coefficient alpha.

Results

The 18 items that were selected to comprise the PSQ-18, as well as their means and standard deviations, are shown in Table 1. The PSQ-18 instrument is provided in Appendix A and the scoring instructions are included in Appendix B (Appendix C provides the long form PSQ-III). As shown in Table 2, all PSQ-18 subscales have generally acceptable internal consistency reliability, although the coefficients for the interpersonal and communication scales fall below the 0.70 standard advocated by Nunnally (1978) for group-level comparisons. Moreover, as displayed in Table 2, PSQ-18 short-form and PSQ-III long-form versions of corresponding subscales are substantially correlated. In addition, as revealed in Table 3, the pattern of correlations among short-form subscales is highly similarly to the pattern of correlations among long-form scales. Finally, as shown in Table 4, many of the PSQ-18 items were substantially correlated with multiple subscales. For example, items tapping satisfaction with communication and time spent with doctor were highly correlated with several other subscales. By contrast, items measuring financial satisfaction and satisfaction with access to care showed fairly good item discrimination across scales. Preliminary PSQ-III and PSQ-18 normative

data for various patient populations and sociodemographic characteristics are shown in Appendix D.

Discussion

This article reports on the development and psychometric properties of a short-form version of the PSQ-III (Marshall et al., 1993). This 18-item instrument, the PSQ-18, retains many characteristics of its full-length counterpart, despite its shortened length. In particular, the PSQ-18 subscales show acceptable internal consistency reliability, especially in view of their abbreviated length. Furthermore, corresponding PSQ-18 and PSQ-III subscales are substantially correlated with one another. With one exception, these correlations exceed 0.90. In addition, both the magnitude of the correlation coefficients and the overall pattern of correlations among PSQ-18 subscales are highly similar to those observed for the PSQ-III. In sum, these preliminary analyses suggest that the PSQ-18 may be appropriate for use in situations where the need for brevity precludes administration of the full-length PSQ-III. We estimate that the PSQ-18 requires about 3-4 minutes to complete whereas the long form PSQ-III requires 9-12 minutes.

We are now pursuing several additional lines of evidence to evaluate more fully the reliability and validity of the PSQ-18. First, we are comparing the psychometric properties of the PSQ-18 with alternative short-form versions of the PSQ-III.[3] Second, inasmuch as the analyses reported here focus on the internal structure of alternative item sets, we are now evaluating the relative ability of the PSQ-18 and alternative instruments to predict key external criteria. Finally, additional research is required to determine the practical

[3]The substantial covariation of subscales measuring satisfaction with physician care (i.e., Communication, Interpersonal Manner, Technical Quality, and Time Spent with Doctor) coupled with the modest reliability of two of these subscales suggests -- at least for certain purposes -- that these 10 items might be combined into a single index. The internal consistency reliability (coefficient alpha) of such a subscale in this data set is 0.89.

utility of distinguishing among separate dimensions of satisfaction with medical care. Substantial covariation was found among most PSQ-18 subscales. Similar findings have been reported on the full-scale PSQ-III (Marshall et al., 1993), indicating that this issue is not unique to the PSQ-18.

Table 1

Univariate Statistics for PSQ-18 Subscales and Constituent Items

Subscale and Item	Mean	SD
General Satisfaction (Mean = 3.58, SD = 0.94)		
3. The medical care I have been receiving is just about perfect. (11)	3.68	1.00
17. I am dissatisfied with some things about the medical care I receive. (49)	3.48	1.11
Technical Quality (Mean = 3.68, SD = 0.76)		
2. I think my doctor's office has everything needed to provide complete care. (8)	3.94	0.91
4. Sometimes doctors make me wonder if their diagnosis is correct. (12)	3.19	0.92
6. When I go for medical care, they are careful to check everything when treating and examining me. (15)	3.74	0.98
14. I have some doubts about the ability of the doctors who treat me. (45)	3.84	0.96
Interpersonal Manner (Mean = 4.09, SD = 0.69)		
10. Doctors act too businesslike and impersonal toward me. (29)	3.88	0.89
11. My doctors treat me in a very friendly and courteous manner. (34)	4.29	0.98
Communication (Mean = 3.74, SD = 0.87)		
1. Doctors are good about explaining the reason for medical tests. (6)	3.09	1.00
13. Doctors sometimes ignore what I tell them. (38)	3.58	1.02
Financial Aspects (Mean = 3.78, SD = 0.94)		
5. I feel confident that I can get the medical care I need without being set back financially. (14)	3.74	1.08
7. I have to pay for more of my medical care than I can afford. (24)	3.83	1.05

Table 1 (Continued)
Univariate Statistics for PSQ-18 Subscales and Constituent Items

Subscale and Item	Mean	SD
Time Spent with Doctor (Mean = 3.59, SD = 0.94)		
12. Those who provide my medical care sometimes hurry too much when they treat me. (35)	3.52	1.08
15. Doctors usually spend plenty of time with me. (46)	3.67	1.00
Accessibility and Convenience (Mean = 3.76, SD = 0.74)		
8. I have easy access to the medical specialists I need. (25)	3.86	0.92
9. Where I get medical care, people have to wait too long for emergency treatment. (28)	3.55	0.98
16. I find it hard to get an appointment for medical care right away. (48)	3.65	1.08
18. I am able to get medical care whenever I need it. (51)	3.96	0.90

Note. (N=2,197). Numbers in parentheses correspond to item placement within the PSQ-III at baseline of the Medical Outcomes Study (Marshall et al., 1993). Possible scores range from 1-5. SD = Standard deviation.

Table 2

Internal Consistency Reliabilities and Correlations between PSQ-III and PSQ-18 Subscales

Subscale	Internal Consistency Reliabilities		*r*
	PSQ-III	PSQ-18	
General Satisfaction	0.88 (6)	0.75 (2)	0.92
Technical Quality	0.85 (10)	0.74 (4)	0.92
Interpersonal Manner	0.82 (7)	0.66 (2)	0.83
Communication	0.82 (5)	0.64 (2)	0.92
Financial Aspects	0.89 (8)	0.73 (2)	0.90
Time Spent with Doctor	0.77 (2)	0.77 (2)	1.00
Accessibility and Convenience	0.86 (12)	0.75 (4)	0.91

Note. (N=2,197). The number of items in each subscale is shown in parentheses. r = Product - moment correlation coefficient.

Table 3

Correlations among PSQ-III and PSQ-18 Subscales

Subscale	1	2	3	4	5	6	7
1. General Satisfaction	--	.74	.57	.66	.30	.65	.64
2. Technical Quality	.81	--	.60	.70	.35	.63	.60
3. Interpersonal Manner	.71	.78	--	.61	.25	.62	.55
4. Communication	.74	.78	.80	--	.31	.64	.56
5. Financial Aspects	.32	.33	.33	.31	--	.23	.31
6 Time Spent with Doctor	.70	.69	.71	.70	.23	--	.58
7. Accessibility and Convenience	.73	.69	.67	.67	.37	.60	--

Note. (N=2,197). PSQ-18 correlations are shown in the upper triangle of the matrix; PSQ-III correlations are shown in the lower triangle of the matrix.

Table 4

Item-Scale Correlations for PSQ-18 Subscales

	Gen	Tech	Int	Com	Fin	Time	Access
General Satisfaction (Gen)							
Item 3	**.71**	.68[a]	.58	.61	.30	.55	.57
Item 17	**.73**	.69[a]	.61	.62	.24	.60	.62
Technical Quality (Tech)							
Item 2	.51[a]	**.50**	.44	.45	.26	.37	.46
Item 4	.57[a]	**.61**	.53	.55	.27	.46	.44
Item 6	.68[a]	**.66**	.62[a]	.68[a]	.30	.59	.58
Item 14	.61[a]	**.64**	.58	.56	.23	.49	.50
Interpersonal Manner (Int)							
Item 10	.56	.59	**.67**	.62	.26	.56	.54
Item 11	.53	.56	**.61**	.58[a]	.18	.52	.49
Communication (Com)							
Item 1	.57[a]	.60[a]	.58[a]	**.61**	.27	.49	.51
Item 13	.59[a]	.63[a]	.55[a]	**.47**	.27	.62[a]	.50
Financial Aspects (Fin)							
Item 5	.36	.35	.35	.35	**.71**	.27	.37
Item 7	.20	.24	.24	.21	**.70**	.13	.25
Time Spent with Doctor (Time)							
Item 12	.65[a]	.64[a]	.64[a]	.64[a]	.23	**.61**	.54
Item 15	.60[a]	.61[a]	.64[a]	.62[a]	.20	**.62**	.54
Accessibility and Convenience (Access)							
Item 8	.52	.53	.49	.48	.31	.42	**.58**
Item 9	.49	.48	.47	.42	.23	.48	**.57**
Item 16	.52	.48	.47	.45	.17	.46	**.63**
Item 18	.57	.52	.50	.50	.25	.47	**.67**

Note. (N=2,197). Correlation coefficients are adjusted downward as necessary to correct for inflation caused by item-scale auto correlation. Complete item content is shown in Table 1. Coefficients in boldface indicate subscale assignment. Standard error of correlation $\simeq$ 0.02.

[a]Indicates that the item-scale correlation is within 2 standard errors of the item-scale correlation for the hypothesized scale.

References

Aday, L. A., Andersen, R., & Fleming, G. V. (1980). Health care in the U.S.: Equitable for whom? Beverly Hills, CA, Sage Publications.

Aday, L. W., Fleming, G. V., & Andersen, R. (1984). Access to medical care in the U.S.: Who has it, who doesn't. Chicago: University of Chicago and Pluribus Press, Inc. (Continuing CHAS Research Series No. 32).

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. Psychometrika, 16, 297.

Davies, A. R., Ware, J. E., Brook, R. H., Peterson, J. R., & Newhouse, J. P. (1986). Consumer acceptance of prepaid and fee-for-service medical care: Results from a randomized controlled trial. Health Services Research, 21, 429-452.

Davies, A. R., & Ware, J. E. (1988). Involving consumers in quality of care assessment. Health Affairs, 7, 33-48.

Hays, R. D., & Hayashi, T. (1990). Beyond internal consistency reliability: Rationale and user's guide for Multitrait Scaling Analysis Program on the microcomputer. Behavior Research Methods, Instruments, and Computers, 22, 167-175.

Marquis, M. S., Davies, A. R., & Ware, J. E. (1983). Patient satisfaction and change in medical care provider: A longitudinal study. Medical Care, 21, 821-829.

Marshall, G. N., Hays, R. D., Sherbourne, C. D., & Wells, K. B. (1993). The structure of patient satisfaction with outpatient medical care. Psychological Assessment, 5, 477-483.

Nunnally, J. (1978). Psychometric Theory, 2nd ed. New York: McGraw-Hill.

Rogers, W., McGlynn, E., Berry, W., Nelson, E., Perrin, E., Zubkoff, M., Greenfield, S., Wells, K. B., Stewart, A. L., Arnold, S., and Ware, J. E. (1992). Methods of sampling. In Stewart, A. L. and Ware, J. E., Jr. (Eds.), Measuring Functional Status and Well-Being: The Medical Outcomes Study Approach. Duke University Press.

Sherbourne, C. D., Hays, R. D., Ordway, L., DiMatteo, M. R., & Kravitz, R. (1992). Antecedents of adherence to medical recommendations: Results from the Medical Outcomes Study. Journal of Behavioral Medicine, 15, 447-468.

Tarlov, A. R., Ware, J. E., Greenfield, S., Nelson, E. C., Perrin, E., & Zubkoff, M. (1989). Medical Outcomes Study: An application of methods for evaluating the results of medical care. Journal of the American Medical Association, 262, 907-913.

Vaccarino, J. M. (1977). Malpractice: The problem in perspective. Journal of the American Medical Association, 238, 861-863.

Ware, J. E. (1978). Effects of acquiescent response set on patient satisfaction ratings. Medical Care, 16, 327-336.

Ware, J. E., & Davies, A. R. (1983). Behavioral consequences of consumer dissatisfaction with medical care. Evaluation and Program Planning, 6, 291-297.

Ware, J. E., Snyder, M. K., Wright, W. R., & Davies, A. R. (1983). Defining and measuring patient satisfaction with medical care. Evaluation and Program Planning, 6, 247-263.

Ware, J. E., Snyder, M. K., & Wright, W. R. (1976a). Development and Validation of Scales to Measure Patient Satisfaction with Medical Care Services. Vol I, Part A: Review of Literature, Overview of Methods, and Results Regarding Construction of Scales. (NTIS Publication No. PB 288-329). Springfield, VA, National Technical Information Service.

Ware, J. E., Snyder, M. K., & Wright, W. R. (1976b). Development and Validation of Scales to Measure Patient Satisfaction with Medical Care Services. Vol I, Part B: Results Regarding Scales Constructed from the Patient Satisfaction Questionnaire and Measures of Other Health Care Perceptions. (NTIS Publication No. PB 288-330). Springfield, VA, National Technical Information Service.

Author Notes

This research was supported by grants from the Agency for Health Care Policy and Research, the National Institute on Aging, The Robert Wood Johnson Foundation, The Henry J. Kaiser Family Foundation, the National Institute of Mental Health, the Pew Charitable Trusts, and RAND. The views expressed are those of the authors and do not necessarily represent those of the sponsors or RAND. The authors gratefully acknowledge the following people who have contributed to this study: Alan B. Cohen and Linda G. Aiken at The Robert Wood Johnson Foundation; Barbara H. Kehrer at The Henry J. Kaiser Family Foundation; Rebecca Rimel and Rosanne Siegel at the Pew Charitable Trusts; Albert P. Williams and Mary Anderson at RAND, and especially MOS staff and consultants, including Sandra H. Berry, Sandra Blau, M. Audrey Burnam, Maureen Carney, Toshi Hayashi, Laural Hill, Judith Perlman, Adam Keller, Stephen Klein, Willard G. Manning, Elizabeth McGlynn, Lynn Ordway, William Rogers, Anita L. Stewart, and John E. Ware. We also appreciate the providers and patients who participated in this study, and Lewin and Associates for their assistance in selecting the study sites.

Address correspondence to: Grant N. Marshall or Ron D. Hays, RAND, 1700 Main Street, Santa Monica, CA 90407-2138.

APPENDIX A

Short-Form Patient Satisfaction Questionnaire (PSQ-18)

SHORT-FORM PATIENT SATISFACTION QUESTIONNAIRE (PSQ-18)

These next questions are about how you feel about the medical care you receive.

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
1. Doctors are good about explaining the reason for medical tests	1	2	3	4	5
2. I think my doctor's office has everything needed to provide complete medical care	1	2	3	4	5
3. The medical care I have been receiving is just about perfect	1	2	3	4	5
4. Sometimes doctors make me wonder if their diagnosis is correct	1	2	3	4	5
5. I feel confident that I can get the medical care I need without being set back financially	1	2	3	4	5
6. When I go for medical care, they are careful to check everything when treating and examining me	1	2	3	4	5
7. I have to pay for more of my medical care than I can afford	1	2	3	4	5
8. I have easy access to the medical specialists I need	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
9. Where I get medical care, people have to wait too long for emergency treatment	1	2	3	4	5
10. Doctors act too businesslike and impersonal toward me	1	2	3	4	5
11. My doctors treat me in a very friendly and courteous manner	1	2	3	4	5
12. Those who provide my medical care sometimes hurry too much when they treat me	1	2	3	4	5
13. Doctors sometimes ignore what I tell them	1	2	3	4	5
14. I have some doubts about the ability of the doctors who treat me	1	2	3	4	5
15. Doctors usually spend plenty of time with me	1	2	3	4	5
16. I find it hard to get an appointment for medical care right away	1	2	3	4	5
17. I am dissatisfied with some things about the medical care I receive	1	2	3	4	5
18. I am able to get medical care whenever I need it	1	2	3	4	5

APPENDIX B

Instructions for Scoring the PSQ-18

Instructions for Scoring the PSQ-18

The PSQ-18 yields separate scores for each of seven different subscales: General Satisfaction (Items 3 and 17); Technical Quality (Items 2, 4, 6, and 14); Interpersonal Manner (Items 10 and 11); Communication (Items 1 and 13); Financial Aspects (Items 5 and 7); Time Spent with Doctor (Items 12 and 15); Accessibility and Convenience (Items 8, 9, 16, and 18).

Some PSQ-18 items are worded so that agreement reflects satisfaction with medical care, whereas other items are worded so that agreement reflects dissatisfaction with medical care. All items should be scored so that high scores reflect satisfaction with medical care (see Appendix B Table 1). After item scoring, items within the same subscale should be averaged together to create the 7 subscale scores.

We recommend that items left blank by respondents (missing data) be ignored when calculating scale scores. In other words, scale scores represent the average for all items in the scale that were answered.

Appendix B Table 1

Scoring Items

Item Numbers	Original Response Value		Scored Value
1, 2, 3, 5, 6, 8, 11, 15, 18	1	---------->	5
	2	---------->	4
	3	---------->	3
	4	---------->	2
	5	---------->	1
4, 7, 9, 10, 12, 13, 14, 16, 17	1	---------->	1
	2	---------->	2
	3	---------->	3
	4	---------->	4
	5	---------->	5

Appendix B Table 2

Creating Scale Scores

Scale	Average These Items
General Satisfaction	3, 17
Technical Quality	2, 4, 6, 14
Interpersonal Manner	10, 11
Communication	1, 13
Financial Aspects	5, 7
Time Spent with Doctor	12, 15
Accessibility and Convenience	8, 9, 16, 18

Note. Items within each scale are averaged after scoring as shown in Appendix Table 1.

APPENDIX C

Long-Form Patient Satisfaction Questionnaire (PSQ-III)

LONG-FORM PATIENT SATISFACTION QUESTIONNAIRE (PSQ-III)

These next questions are about how you feel about the medical care you receive.

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
1. If I need hospital care, I can get admitted without any trouble.....	1	2	3	4	5
2. Doctors need to be more thorough in treating and examining me.....	1	2	3	4	5
3. I am very satisfied with the medical care I receive.....	1	2	3	4	5
4. I worry sometimes about having to pay large medical bills.....	1	2	3	4	5
5. It is easy for me to get medical care in an emergency.....	1	2	3	4	5
6. Doctors are good about explaining the reason for medical tests.....	1	2	3	4	5
7. I am usually kept waiting for a long time when I am at the doctor's office...	1	2	3	4	5
8. I think my doctor's office has everything needed to provide complete medical care.....	1	2	3	4	5
9. The doctors who treat me should give me more respect.....	1	2	3	4	5
10. Sometimes it is a problem to cover my share of the cost for a medical care visit.....	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
11. The medical care I have been receiving is just about perfect.....	1	2	3	4	5
12. Sometimes doctors make me wonder if their diagnosis is correct.....	1	2	3	4	5
13. During my medical visits, I am always allowed to say everything that I think is important.....	1	2	3	4	5
14. I feel confident that I can get the medical care I need without being set back financially.....	1	2	3	4	5
15. When I go for medical care, they are careful to check everything when treating and examining me.....	1	2	3	4	5
16. It's hard for me to get medical care on short notice.....	1	2	3	4	5
17. The doctors who treat me have a genuine interest in me as a.person.....	1	2	3	4	5
18. Sometimes doctors use medical terms without explaining what they mean.....	1	2	3	4	5
19. Sometime I go without the medical care I need because it is too expensive.....	1	2	3	4	5
20. The office hours when I can get medical care are convenient (good) for me.....	1	2	3	4	5
21. There are things about the medical system I receive my care from that need to be improved.....	1	2	3	4	5
22. The office where I get medical care should be open for more hours than it is.....	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
23. The medical staff that treats me knows about the latest medical developments.....	1	2	3	4	5
24. I have to pay for more of my medical care than I can afford.....	1	2	3	4	5
25. I have easy access to the medical specialists I need.....	1	2	3	4	5
26. Sometimes doctors make me feel foolish.....	1	2	3	4	
27. Regardless of the health problems I have now or develop later, I feel protected from financial hardship.....	1	2	3	4	5
28. Where I get medical care, people have to wait too long for emergency treatment.....	1	2	3	4	5
29. Doctors act too businesslike and impersonal toward me.....	1	2	3	4	5
30. There is a crisis in health care in the United States today.....	1	2	3	4	5
31. Doctors never expose me to unnecessary risk.....	1	2	3	4	5
32. The amount I have to pay to cover or insure my medical care needs is reasonable	1	2	3	4	5
33. There are some things about the medical care I receive that could be better.....	1	2	3	4	5
34. My doctors treat me in a very friendly and courteous manner.....	1	2	3	4	5
35. Those who provide my medical care sometimes hurry too much when they treat me.....	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
36. Some of the doctors I have seen lack experience with my medical problems.	1	2	3	4	5
37. Places where I can get medical care are very conveniently located.....	1	2	3	4	5
38. Doctors sometimes ignore what I tell them.....	1	2	3	4	5
39. When I am receiving medical care, they should pay more attention to my privacy.....	1	2	3	4	5
40. If I have a medical question, I can reach a doctor for help without any problem.....	1	2	3	4	5
41. Doctors rarely give me advice about ways to avoid illness and stay healthy.	1	2	3	4	5
42. All things considered, the medical care I receive is excellent.....	1	2	3	4	5
43. Doctors listen carefully to what I have to say.....	1	2	3	4	5
44. I feel insured and protected financially against all possible medical problems.....	1	2	3	4	5
45. I have some doubts about the ability of the doctors who treat me.....	1	2	3	4	5
46. Doctors usually spend plenty of time with me.....	1	2	3	4	5
47. Doctors always do their best to keep me from worrying.....	1	2	3	4	5
48. I find it hard to get an appointment for medical care right away.....	1	2	3	4	5
49. I am dissatisfied with some things about the medical care I receive.....	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
50. My doctors are very competent and well-trained.....	1	2	3	4	5
51. I am able to get medical are whenever I need it.....	1	2	3	4	5

APPENDIX D

PSQ-III and PSQ-18 Subscale Scores by Demographic Groups

APPENDIX D
Table 1

PSQ-18 Subscale Scores by Demographic Groups

PSQ-18 Subscale	Gender		Race			Employment Status[a]	
	Males (N=871)	Females (N=1326)	White (N=1771)	African-American (N=304)	Other (N=426)	Employed (N=1077)	Unemployed (N=1120)
General Satisfaction	65.05 (22.96)	64.23 (23.89)	64.41 (23.36)	64.84 (24.44)	65.17 (24.22)	62.06 (23.66)	66.96 (23.15)
Technical Quality	67.14 (18.19)	67.07 (19.60)	67.16 (18.67)	66.87 (21.06)	66.84 (20.58)	65.49 (19.53)	68.64 (18.45)
Interpersonal Manner	77.81 (16.58)	76.85 (17.81)	77.25 (17.40)	78.18 (16.80)	77.15 (17.06)	75.85 (18.40)	78.57 (16.14)
Communication	69.40 (20.49)	67.96 (22.46)	68.54 (21.80)	69.51 (21.27)	68.50 (21.34)	66.66 (21.91)	70.34 (21.37)
Financial Aspects	71.36 (22.91)	68.38 (23.87)	69.41 (23.80)	70.92 (22.93)	70.21 (22.40)	69.31 (24.49)	69.81 (22.58)
Time Spent with Doctor	65.38 (22.75)	64.36 (23.82)	64.71 (23.50)	66.78 (22.04)	64.99 (22.98)	61.88 (23.91)	67.53 (22.55)
Accessibility and Convenience	69.93 (18.32)	68.29 (18.61)	69.60 (18.06)	67.02 (19.65)	66.22 (20.08)	67.81 (18.65)	70.04 (18.31)

PSQ-18 Subscale	Marital Status		Education		Income[b]	
	Married (N=1247)	Not Married (N=950)	< High School (N=345)	≥ High School (N=1852)	Low (N=945)	High (N=1252)
General Satisfaction	65.25 (23.00)	63.66 (24.18)	67.97 (22.62)	63.92 (23.64)	65.53 (23.78)	63.83 (23.31)
Technical Quality	67.44 (18.63)	66.64 (19.59)	68.62 (19.25)	66.81 (19.00)	67.50 (19.19)	66.79 (18.94)
Interpersonal Manner	77.77 (16.79)	76.53 (18.01)	78.62 (16.47)	76.97 (17.48)	77.58 (17.49)	76.97 (17.22)
Communication	69.32 (21.44)	67.50 (22.02)	70.68 (21.43)	68.13 (21.74)	69.57 (21.69)	67.76 (21.70)
Financial Aspects	71.14 (22.56)	67.51 (24.61)	66.84 (23.17)	70.08 (23.57)	66.84 (23.82)	71.61 (23.11)
Time Spent with Doctor	64.92 (23.11)	64.57 (23.77)	68.41 (21.92)	64.09 (23.61)	66.24 (23.13)	63.65 (23.54)
Accessibility and Convenience	69.64 (18.60)	68.03 (18.36)	68.47 (18.64)	69.03 (18.49)	67.82 (19.26)	69.79 (17.88)

[a]Employed group includes all persons working full - or part-time. Unemployed group includes all persons not receiving payment for full - or part-time employment.

[b]Low Income: Mean = 9,363; Standard Deviation = 3,936. High Income: Mean = 30,894; Standard Deviation = 14,599. Income is adjusted for family size and is expressed in 1985 dollars.

APPENDIX D
Table 1 (Continued)

PSQ-18 Subscale Scores by Demographic Groups

PSQ-18 Subscale	Age			
	18-44 (N=624)	45-64 (N=728)	65-74 (N=582)	75+ (N=263)
General Satisfaction	56.47 (23.99)	65.30 (22.86)	70.02 (21.88)	69.33 (22.55)
Technical Quality	61.46 (19.93)	68.17 (18.82)	70.42 (17.07)	70.12 (18.82)
Interpersonal Manner	72.60 (19.30)	77.94 (16.90)	80.26 (14.95)	79.58 (16.32)
Communication	62.36 (22.27)	68.82 (21.83)	72.91 (20.43)	72.72 (19.28)
Financial Aspects	64.87 (25.67)	70.30 (23.86)	73.46 (20.37)	70.09 (22.03)
Time Spent with Doctor	57.67 (24.69)	65.47 (23.02)	69.26 (21.52)	69.68 (21.24)
Accessibility and Convenience	63.68 (18.87)	70.05 (18.57)	72.00 (17.41)	71.58 (17.29)

PSQ-18 Subscale	Medical Condition[c]			
	Hypertension (N=1293)	Diabetes (N=489)	Heart Disease (N=298)	Depressive Symptoms (N=874)
General Satisfaction	67.97 (21.81)	69.35 (22.10)	69.71 (22.92)	57.26 (25.24)
Technical Quality	69.34 (17.57)	70.77 (18.31)	70.60 (18.69)	61.55 (20.85)
Interpersonal Manner	79.09 (15.49)	80.12 (15.78)	80.96 (14.62)	73.04 (20.02)
Communication	71.34 (19.75)	73.05 (20.84)	73.15 (20.14)	61.94 (23.89)
Financial Aspects	72.25 (21.32)	71.67 (22.42)	71.02 (23.81)	63.67 (25.64)
Time Spent with Doctor	67.62 (21.92)	69.20 (22.03)	69.29 (21.52)	58.08 (25.34)
Accessibility and Convenience	70.76 (17.39)	71.95 (18.07)	73.06 (18.26)	64.59 (19.92)

[c]All patients have at least one of these medical conditions.

APPENDIX D
Table 2

PSQ-III Subscale Scores by Demographic Groups

PSQ-III Subscale	Gender		Race			Employment Status[a]	
	Males (N=871)	Females (N=1326)	White (N=1771)	African-American (N=304)	Other (N=426)	Employed (N=1077)	Unemployed (N=1120)
General Satisfaction	63.74 (19.24)	63.19 (20.26)	63.57 (19.73)	62.86 (20.50)	62.74 (20.41)	61.03 (19.94)	65.70 (19.52)
Technical Quality	67.25 (15.48)	66.63 (16.53)	67.16 (15.90)	66.03 (17.34)	65.71 (17.01)	65.38 (16.48)	68.32 (15.65)
Interpersonal Manner	73.35 (14.83)	70.82 (16.76)	72.02 (16.06)	71.86 (15.74)	70.99 (16.07)	70.27 (16.59)	73.32 (15.40)
Communication	71.59 (17.28)	70.31 (19.26)	70.72 (18.67)	71.93 (17.87)	71.24 (17.84)	69.55 (18.54)	72.03 (18.40)
Financial Aspects	67.43 (20.89)	63.75 (22.00)	65.13 (22.03)	66.16 (20.26)	65.55 (19.94)	64.73 (22.58)	65.67 (20.69)
Time Spent with Doctor	65.38 (22.75)	66.63 (16.53)	64.71 (23.50)	66.78 (22.05)	64.99 (22.98)	61.88 (23.91)	67.53 (22.56)
Accessibility and Convenience	72.01 (14.77)	70.16 (15.36)	71.55 (14.79)	68.75 (16.35)	68.14 (16.30)	69.42 (15.34)	72.31 (14.85)

PSQ-III Subscale	Marital Status		Education		Income[b]	
	Married (N=1247)	Not Married (N=950)	< High School (N=345)	≥ High School (N=1852)	Low (N=945)	High (N=1252)
General Satisfaction	63.69 (19.38)	63.04 (20.48)	66.29 (19.42)	62.87 (19.90)	64.31 (20.08)	62.73 (19.67)
Technical Quality	67.28 (15.91)	66.35 (16.40)	67.48 (15.76)	66.77 (16.19)	66.87 (16.22)	66.88 (16.06)
Interpersonal Manner	72.45 (15.84)	71.00 (16.32)	72.11 (15.97)	71.77 (16.09)	71.45 (16.52)	72.11 (15.71)
Communication	71.12 (18.39)	70.41 (18.66)	71.82 (18.24)	70.63 (18.55)	71.07 (18.64)	70.63 (18.41)
Financial Aspects	67.07 (20.91)	62.77 (22.33)	61.62 (21.50)	65.88 (21.60)	62.20 (21.89)	67.48 (21.17)
Time Spent with Doctor	64.92 (23.11)	64.57 (23.77)	68.41 (21.92)	64.09 (23.61)	66.24 (23.13)	63.65 (23.54)
Accessibility and Convenience	71.74 (14.94)	69.77 (15.36)	70.53 (15.00)	70.96 (15.19)	69.98 (15.64)	71.58 (14.75)

[a]Employed group includes all persons working full - or part-time. Unemployed group includes all persons not receiving payment for full - or part-time employment.

[b]Low Income: Mean = 9,363; Standard Deviation = 3,936. High Income: Mean = 30, 894; Standard Deviation = 14, 599. Income is adjusted for family size and is expressed in 1985 dollars.

APPENDIX D
Table 2 (Continued)

PSQ-III Subscale Scores by Demographic Groups

PSQ-III Subscale	Age			
	18-44 (N=624)	45-64 (N=728)	65-74 (N=582)	75+ (N=263)
General Satisfaction	56.48 (20.37)	63.93 (19.30)	68.12 (18.76)	68.00 (17.88)
Technical Quality	62.11 (16.57)	67.58 (16.15)	69.91 (14.85)	69.56 (15.19)
Interpersonal Manner	66.20 (17.45)	72.52 (15.59)	75.45 (13.87)	75.19 (14.85)
Communication	66.32 (18.83)	71.30 (18.49)	74.00 (17.84)	73.11 (17.20)
Financial Aspects	60.06 (23.42)	66.07 (21.89)	69.00 (18.94)	66.66 (19.87)
Time Spent with Doctor	57.67 (24.69)	65.47 (23.02)	69.26 (21.52)	69.68 (21.24)
Accessibility and Convenience	65.69 (15.63)	71.62 (14.95)	74.16 (13.82)	73.97 (14.19)

PSQ-III Subscale	Medical Condition[c]			
	Hypertension (N=1293)	Diabetes (N=489)	Heart Disease (N=298)	Depressive Symptoms (N=874)
General Satisfaction	66.30 (18.34)	67.08 (19.03)	69.11 (18.33)	57.22 (21.42)
Technical Quality	68.81 (14.87)	70.19 (15.63)	70.42 (15.74)	62.07 (17.46)
Interpersonal Manner	74.13 (14.27)	74.61 (15.22)	76.26 (14.01)	66.66 (18.10)
Communication	72.88 (17.04)	74.37 (17.93)	74.02 (17.50)	65.63 (20.24)
Financial Aspects	67.97 (19.81)	67.47 (21.04)	66.56 (22.26)	58.93 (23.04)
Time Spent with Doctor	67.62 (21.92)	69.20 (22.03)	69.29 (21.52)	58.08 (25.34)
Accessibility and Convenience	72.61 (14.07)	73.43 (14.76)	74.81 (15.16)	66.62 (16.23)

[c]All patients have at least one of these medical conditions.